

# Psychological Implications of Lung Cancer Screening & Patient Perceptions of Benefits, Harms, and Risk

By

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## **Abstract for the Master's Paper**

**Introduction:** Low Dose Computed Tomographic (LDCT) scanning for lung cancer screening recently received a Grade B recommendation from the United States Preventive Services Task Force (USPSTF). Many uncertainties regarding potential harms of this relatively new cancer screening modality exist. In this paper I explore the psychological implications of lung cancer screening and report findings from a study on patient perceptions of potential benefits and harms of lung cancer screening, along with perceptions of lung cancer risk.

**Methods:** I conducted a systematic review of the recent literature to show current evidence of psychological harms of lung cancer screening. I used this review to guide my research and discussion of results from a survey conducted among general medicine clinic patients who were at increased risk for lung cancer, due to long-term smoking history. This study surveyed participants on their understanding of potential benefits and risks of LDCT screening, as well as their thoughts about the screening process in general and their personal risk profile.

**Results:** After reviewing 1088 abstracts, 12 studies met inclusion criteria. The studies found that all participants have relatively high cancer risk perceptions and that people with abnormal screen results experienced increased distress. The studies had mixed results regarding changes in distress for the screening groups as a whole (regardless of their screening outcome). Overall, distress for all participants seems to return to baseline over time. My survey study found that individuals who are eligible for screening overestimate the mortality benefits of screening, underestimate the harms of false positives and additional diagnostic and invasive procedures, and overestimate their personal risk of being diagnosed with and dying from lung cancer. When asked why people should get screened for lung cancer, participants most frequently report early detection and early treatment leading to better health outcomes.

**Conclusion:** Abnormal lung cancer screening findings and surveillance of pulmonary nodules are distressing for patients. However, we lack adequate, high-quality, generalizable evidence to make conclusions about the screening experience for all participants, regardless of screening outcome. Eligible screening patients who were part of my survey study were not familiar with the screening process and were overly-optimistic about the precision and effectiveness of LDCT screening. Patients may make more informed choices if they are aware of the potential harms and their personal risk of suffering from lung cancer.

## Preface

*It is common knowledge today that smoking is directly linked to lung cancer and cardiovascular disease, some of the most common causes of death in the U.S. The first claims that tobacco smoke was a risk factor for lung cancer came in 1912, with much skepticism following until the 1950's and 60's.<sup>1</sup> Evidence for increasing incidence of male lung cancer in the 1930's was based on official mortality statistics and pathology reports from autopsies among pulmonary specialist physicians.<sup>1</sup> Plausible etiologies were debated including tobacco, domestic fire smoke, road tars used in construction, and possibly even late sequelae from infectious diseases such as influenza or tuberculosis.<sup>1</sup> In a 1953 experiment researchers painted tobacco tar on the skin of mice and demonstrated growth of tumors on the animals.<sup>2</sup> Large tobacco companies were quick to respond to these claims and tobacco sales continued to rise until peaking in 1982.<sup>2</sup> Much of the later decline in domestic sales may be attributed to the efforts of the U.S. Surgeon General's office, which has made tobacco use a pre-eminent concern over the last 4 decades. In 1962 the Surgeon General enlisted a committee of experts which reviewed over 7,000 articles and in January of 1964 the Surgeon General issued a report highlighting the negative effects of tobacco, ultimately concluding that smoking was responsible for a 70 percent increase in mortality and a nine to ten-fold increase in lung cancer risk compared to non-smokers.<sup>3</sup>*

*Fifty years later smoking still contributes to worldwide morbidity and mortality. Currently smoking is associated with 440,000 premature deaths and \$193 billion of health care costs annually in the U.S.; about 46 million American adults (~20% of the population) continue to smoke.<sup>4</sup> There is marked disparity among education levels: 41.3% usage for those with GED*

*compared to 5.7% usage among those with a graduate degree; and among income level: 31.5% usage for those below vs. 19.6% usage for those at or above the poverty level.<sup>4</sup> Locally, smoking in NC has a higher prevalence than the national average: 20.3% vs. 17.9% in one survey from 2011.<sup>5</sup>*

*Technology is ever-advancing, attempting to improve health by detecting cancer earlier in hopes to improve the treatment of disease.*

# Psychological Harms of Lung Cancer Screening: A Systematic Review

## **Abstract**

**Background:** Lung cancer screening with LDCT has recently been recommended for individuals ages 55 to 80 with a 30 pack-year smoking history based on a positive balance of benefits and harms. However, there is significant potential for screening to have psychological effects on patients. In this review, I assess the available literature regarding the psychological effects of screening and indeterminate pulmonary findings.

**Methods:** Using standardized methods, I performed a systematic review of the literature to synthesize available evidence regarding the psychological effects of lung cancer screening on patients at increased risk of lung cancer. I searched Medline, CINAHL, and PsycINFO databases from 2002-2014 for cohort, cross-sectional, randomized control, and qualitative studies for various psychological harms associated with screening. I followed this search with standardized data abstraction and quality rating processes for eligible studies. I then developed an overall, qualitative synthesis of study results and conclusions.

**Results:** I included twelve studies in the review, organizing them into three categories: 1) screening in asbestos-exposed Europeans, 2) surveillance of pulmonary nodules, 3) screening in large cancer screening trials. The European asbestos studies found mixed results regarding anxiety scores in the samples as a whole but were concordant in that individuals with abnormal results suffered from increased anxiety. The pulmonary nodule studies found increased anxiety and confusion regarding the finding and surveillance of pulmonary nodules. The cancer screening trial studies found varying results for the study groups as a whole, but the highest quality studies found increased anxiety in those with abnormal screening results, and that all



participant groups had relatively high cancer risk perceptions. Most study participants were in relatively good physical and mental health at baseline. One study suggested that the common practice of measuring psychological status just prior to screening may not represent an accurate baseline in participants, due to anxiety surrounding the screening process.

**Conclusion:** The common practice of measuring psychological variables immediately prior to screening may give a false impression of participants' baseline condition, given the anxiety around the time of screening. Good quality and generalizable evidence regarding psychological effects of participating in lung cancer screening is lacking, but there is general agreement that abnormal lung cancer screening findings and surveillance of pulmonary nodules is distressing for patients. This is a clinically important conclusion given the high likelihood of abnormal screening results that necessitate further management in individuals eligible for lung cancer screening.

## **Introduction**

In July, 2013 the USPSTF published a systematic review on lung cancer screening; the conclusions based on the past decades of various trials gave heavy weight to a recent, large, American trial of “good-quality:” the National Lung Screening Trial (NLST).<sup>6</sup> The NLST enrolled 53,554 people at increased risk for lung cancer based on smoking history and found that screening with LDCT vs. chest x-ray resulted in a 20% reduction in lung cancer mortality, and a 6.7% reduction in all-cause mortality.<sup>7</sup> Later in 2013 the USPSTF updated its recommendation for lung cancer screening from an I-statement (insufficient evidence), to a grade B-recommendation concluding that for those at increased risk of lung cancer, there is “moderate certainty... of moderate net benefit” of LDCT screening.<sup>8</sup>

The NLST reported that through three rounds of screening over 2 years, 39.1% of those in the LDCT group received at least one abnormal screening results; 96.4% of these were false-positive results that involved additional diagnostic and invasive testing for confirmation.<sup>7</sup> Because of the high false positive rate in individuals with long-term smoking history, lung cancer screening has been controversial regarding the balance of benefit from reduced mortality with possible harms.<sup>9</sup> Possible physical harms include invasive procedures required to reach definitive diagnosis, and radiation exposure. Overdiagnosis is also highly probable, represented by the reported excess lung cancers diagnosed in the LDCT arm of the NLST. Financial and opportunity costs of time spent and medical resource utilization should also be weighed against potential benefits. Another important factor in overall well-being of patients in screening programs is their psychological wellbeing; this aspect has not been examined to the same degree as physical harms of screening.<sup>6</sup> The goal of this review is to investigate the literature regarding

psychological effects of lung cancer screening with special attention to surveillance of indeterminate findings, and anxiety and knowledge regarding lung cancer specific risk. This review also serves to guide and inform my personal research regarding risk perceptions among those eligible for screening as they balance perceived benefits and harms of their potential experience with lung cancer screening.

## **Methods:**

### Key Questions:

1. What are the psychological harms associated with lung cancer screening?
2. What are the psychological effects of indeterminate pulmonary findings such as lung nodules and other abnormalities that require further testing or surveillance?

### Eligibility Criteria

I used a PICOTTS table (Populations, Interventions, Comparisons, Outcomes, Timing, Settings, and Study designs) to frame the questions answered in this review (Table 1). Given that widespread implementation LDCT screening was only recently recommended, these criteria were purposefully broad to maximize sensitivity of the search. The population of interest was individuals at increased risk for lung cancer undergoing lung cancer screening (by any modality), or surveillance of an indeterminate lung finding, excluding individuals with an existing lung cancer diagnosis. The intervention studied is the screening or surveillance process and any subsequent diagnoses that may result from participation in screening. I allowed multiple comparator groups including: individuals declining screening, individuals at baseline prior to participating in screening, the various arms of a screening trial, or general population norms. I

considered a wide array of outcomes to measure psychological effects such as cognitive and behavioral components of quality of life, general anxiety or distress measures, problems with sleep, fear, discomfort, stigma, health care adherence or utilization, and psychiatric diagnoses.

To focus on current screening modalities and relevant demographics, the time frame of the search was Jan 1, 2002 to Dec 31, 2013; roughly the last ten years. The year 2002 was also chosen because the research group in collaboration with this search had already begun searching literature from this date. I focused only on studies from Organisation for Economic Co-operation and Development countries to improve generalizability of samples, study techniques, and publication methods. The study types included were prospective and retrospective cohort, randomized controlled trials, case-control, and cross-sectional studies, and both quantitative and qualitative studies were considered to collect data from various possible sources. I believed that cross-sectional studies could be an important source of information, and few randomized studies would have been performed with valid outcome measures of interest. The search was limited to peer-reviewed, English-language studies that were published and searchable in the databases used for this review.

### Search Strategy

On Feb 17, 2014 we performed a systematic search of the databases PUBMED, CINAHL, and PsycInfo using the search strings found in Appendix B.

### Study Selection

After identifying articles by the search strategy, I screened studies by title and abstract excluding findings that were irrelevant to the key questions of the search. At this stage, I was

blinded to study authors, but used article title, journal name, and abstract to determine relevance. Various types of articles including reviews, editorials, and other commentaries were included at this stage to search references for any articles missed by the database search string. I hand-searched reviews for additional relevant references. Though dual review of articles would be ideal, I reviewed abstracts and full text of all articles alone given that the goal of this review was to inform an area important to the research presented later in this paper, rather than an ultimate goal of publishing this review as a stand-alone article.

Articles selected for full text review included the following study designs: prospective and retrospective cohort, cross-sectional (quantitative and qualitative), and randomized controlled trials.

### Data Collection Processes

I collected information from the selected articles regarding psychological harms of lung cancer screening into a standardized data form to abstract relevant information from each article selected. This included the following information: study population characteristics and recruitment methods, study setting and design, interventions, comparator groups, instruments used to measure outcomes, measurement intervals, and overall study results.

The studies included use many different measurement tools. The Psychological Consequences Questionnaire (PCQ) was first used in breast cancer screening and was slightly modified in the Paris study for use in lung cancer screening.<sup>10,11</sup> The Impact of Events Scale-Lung Cancer (IES) is a modified scale used to measure distress through sub-scales of intrusion and avoidance of stressful events.<sup>12</sup> The Medical Outcomes Study Short Form 12 (SF-12) measures general health related quality of life and contains a psychological component.<sup>13</sup> The

Euroqol-5D (EQ-5D) is a measure of health related quality of life which includes measures of anxiety and depression.<sup>14</sup> The State-Trait Anxiety Inventory (STAI-6) contains six items related to anxiety (calm, tense, upset, relax, content, worried) to determine relative anxiety levels.<sup>15</sup> The Consequences of Screening in Lung Cancer (COS) questionnaire was originally developed for breast cancer screening; it measures anxiety, sleep, behavior, dejection, stigma, and guilt, among other psychosocial elements.<sup>16</sup> These instruments have been validated and studies of validation techniques are referenced here for each instrument. Some studies developed customized measurement instruments of distress and risk perception; these studies referenced external validation sources of their instruments when necessary.

#### Risk of bias in individual studies

I assessed articles for quality and strength of evidence using a grading scheme similar to that of the USPSTF. I recorded overall magnitude of effect measured in each study and judged each article by the overall certainty of effect (based the underlying study design and execution). I rated internal and external validity as good, fair, or poor using the USPSTF critical appraisal procedure manual.<sup>17</sup> Internal validity ratings were based on relative degree of selection, measurement, and confounding biases and are a marker of how well the study answers the question set forth by that particular study.<sup>18</sup> External validity ratings were based on how well the study's results could be applied to answer this reviews key questions and are framed by the limitations inherent within each study.<sup>19</sup> These guidelines are available in Appendix D.

#### Synthesis

I assessed the strength of evidence for all studies included using USPSTF procedure manual guidelines which consider six key questions to critical appraisal. This involves rating the body of evidence based on included studies' appropriate design, quality, generalizability, number of studies and participant number within each study, and consistency of results across studies, among other factors.<sup>20</sup> By considering the available evidence I judged a conceptual confidence interval to generate a strength of evidence rating based on criteria in Appendix D, Table a.

## **Results:**

### **Study Selection:**

The study selection process is outlined in the figure provided from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Appendix C). I identified twelve studies to inform the key questions of this review. The search strategy discovered a total of 1088 unique articles that were screened by title and abstract. Hand searching references from reviews yielded one additional unique study for inclusion in full text review. I performed a full text review of 21 articles (including 4 reviews); to confirm studies reported relevant outcomes for the population of interest. Nine studies were excluded after full-text review including four reviews, two duplicate studies published in different journals, two studies with inappropriate outcomes, and one study with inappropriate comparison groups.

### **Study Characteristics:**

The studies included were grouped into 3 categories based on their sample populations. The first category involves lung cancer screening in European populations of asbestos-exposed

workers and includes two studies, both of which were prospective cohort samples. Outcomes in these studies were relative health-anxiety.

In the second category, three studies examined pulmonary nodules; two were qualitative cross-sectional interview studies that examined anxiety regarding indeterminate findings, one was a prospective cohort in a Cleveland Clinic lung cancer screening trial that focused on quality of life ratings and health care utilization.

The last and largest category contains seven studies that involve samples from large established screening trials. One study was a retrospective cohort sample from the Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial. The rest were prospective cohorts: three studies used samples from the Dutch-NELSON trial; two of these studies were the same sample but measured different outcomes. One study used a sample from the Danish Lung Cancer Screening Trial (DLCST), one evaluated participants of the Pittsburgh Lung Screening Trial, and one evaluated participants of the American NLST. The outcomes in these studies involved lung cancer distress, health-related quality of life, anxiety, medical adherence, and risk perception.

### Summary Measures

Category 1 studies involved lung cancer screening in European, asbestos-exposed workers. Vierikko's study in Finland found anxiety decreased in all participants one year after high-resolution lung CT compared to baseline.<sup>21</sup> The French asbestos sample showed increased abnormal PCQ scores (associated with greater distress) in individuals six months after screening compared to baseline (32.6% vs. 20.5% with abnormal score); additional analysis showed greater distress in those with abnormal findings, particularly pleural plaque and pulmonary nodules.<sup>10</sup>



Category 2 studies involving pulmonary nodules examined the psychological burden of imaging surveillance and the uncertainty involved in receiving a diagnosis of a non-cancerous, indeterminate lung finding. In the Cleveland Clinic Screening Study, patients notified of pulmonary nodules had lower EQ-5D scores as well as increased imaging use at six-month follow up compared to those with normal screen results.<sup>22</sup> The two qualitative studies involved interviews with patients about their experience of being diagnosed with a pulmonary nodule. Most patients initially assumes nodules were cancerous, almost all experienced at least mild distress upon diagnosis, some experienced distress lasting months, and many experienced frustration with physicians not fully addressing their concerns.<sup>23,24</sup> Though mild distress is not defined, Slatore categorizes patient responses regarding worry and intrusive thoughts that do not impair daily activities as “mild”.<sup>23</sup>

Category 3 studies mostly involved psychological questionnaires in samples of participants in large screening trials. NLST participants in the screen arm did not have statistically significant changes in risk perception from baseline screen to 1-year follow up as a whole, or when stratified by smoking status or screen result; changes in smoking status at follow up were not associated with changes in risk perception.<sup>25</sup> DLCST participants in both control and screening arms (only those with negative screen results) had worse COS scores; there was no difference in mean increase of scores between screen and control arms.<sup>26</sup>

Among NELSON trial participants, one study measured baseline health-related quality of life using the SF-12, EQ-5D, STAI-6, and a lung-cancer-specific distress scale. Compared to baseline (prior to randomization, on average 165 days before screening) all participants had worse scores just prior to screening. Shortly after screening, lung-cancer specific distress scores were clinically elevated in those with indeterminate results.<sup>27</sup> Two studies using the same sample

of NELSON participants examined different outcomes. One reported levels of discomfort experienced by lung cancer screening patients (50.5% of respondents report dreading the screening results), as well as health-related quality of life: no metrics (SF-12, EQ-5D, STAI-6, IES) had clinically relevant changes over time.<sup>28</sup> The second study showed participants with higher risk perceptions prior to screening had higher distress and mental SF-12 component scores 6-months after screening; overall, fewer participants perceived their risk as high at follow up compared to 1-day before screening (10.5% vs. 14.6%).<sup>29</sup>

Participants in the Pittsburgh Lung Screening Trial had high baseline cancer risk perceptions that decrease after receiving a negative screen result. Those with non-negative screen results had increased STAI-6 and “fear of cancer” scores; anxiety increases were greater among current smokers, those with lower education, and those unmarried.<sup>30</sup> There was one retrospective study in this category; it examined screening adherence rates in those with false positive vs. negative lung cancer screening results among participants in the PLCO trial. Participants with a false positive result had over 50% greater non-adherence and sub-group analysis showed increased non-adherence among African Americans (OR = 1.5), women (OR = 1.4), current smokers vs. never smokers (OR = 1.4), and older participants.<sup>31</sup>

These results, and other individual study characteristics, are summarized in Appendix E.

#### Quality:

Category 1: The European-asbestos studies were rated poor regarding external validity because of the special population of asbestos-exposed workers, the use of nationalized health systems in France and Finland, and use of High-Resolution CT, whereas American lung cancer

screening protocols employ LDCT. One study received a poor rating for internal validity due to the high proportion of symptomatic participants, as well as relatively low retention of participants with false positive screening results (positive results were excluded).

Category 2: Both qualitative studies were rated as good for internal validity based on well documented and appropriate study design, data collection and analysis, and overall clarity of the study (criteria in Appendix D). One of the qualitative studies was rated poor regarding external validity; this study was performed in a Veteran's Affairs hospital, the sample has unique distinctions compared to the general population at increased risk for lung cancer. The Mazzone study had an external validity rating of poor because of the use of chest-x-ray as the screening mode, and because the sample had higher EQ-5D results than the general population matched for age; I would expect those eligible for lung cancer screening to have notably reduced quality of life scores, given extensive smoking history and associated comorbidities.

Category 3: The 2010 study by van den Bergh received a fair internal validity rating due to low response rates for all 4 measurement times, but was notable for its use of multiple well-documented measurement instruments, four different measurement points with low loss-to-follow up, and detailed statistical analysis section. The Bunge and Byrne studies were the only prospective, non-qualitative study that received good ratings for internal validity. The 2008 van den Bergh study was given a poor external validity rating due to the NELSON trial involving a European screening population (though many studies received a fair rating for this purpose). Additionally, the baseline sample health related quality of life scores were noted to be the same as that of the general population. As mentioned above, I would expect those eligible for lung cancer screening to have notably reduced quality of life scores. NELSON trial eligibility criteria require roughly half the smoking history as the NLST: around 15 pack-years, so these

participants are likely not as heavy smokers as people that might participate in American lung cancer screening programs.

I gave most articles fair ratings for internal validity based on minor flaws in research design, attrition and differential loss to follow up, variations in baseline groups, or other flaws in the criteria outlined in Appendix D.

Participation bias likely explains the relatively high mental and physical health appearing among participants of lung screening trials; additionally these participants were overwhelmingly white, with high levels of education. These trials were conducted in major academic centers with highly specialized clinicians and advanced technology, and results may not be relevant to application among the general U.S. population, therefore none of these articles received better than a fair rating for external validity.

Quality grades for each study are shown in Appendix E.

#### Risk of bias across studies

This search was limited to English language articles and so studies that were published in other languages, or have yet to be translated into English, were not included. Other biases result from only searching through published literature that is accessible through the databases used in this search. Publication bias and language bias are inherent flaws of the search strategy that would be difficult to overcome given the limited resources of my search strategy.

#### Strength of Evidence

The certainty of evidence for key question #1 (what are the psychological harms of screening?) is low given the limited number of good quality studies and the inconsistency of

some outcomes between studies. The certainty of evidence for key question #2 (what are the psychological effects of indeterminate pulmonary findings?) is moderate and approaching high, but is limited by the number of high quality studies. The generalizability of the results is a major limiting factor and the short time frame of the studies means that we cannot observe important long-term psychological effects.

## **Conclusion**

Overall there is mixed evidence regarding psychological effects of lung cancer screening. Category 1 studies had mixed results among populations of asbestos-exposed workers; though both showed increased anxiety in individuals with abnormal screening results, only the larger, higher quality French study showed higher psychological distress among all those screened, regardless of result. The Category 2 studies conclude that the finding of a pulmonary nodule is distressing and imaging use increases after such finding. The category 3 studies are also variable in conclusions. Though all showed increased anxiety in individuals with abnormal screening results (by measurements on EQ-5D, IES, and STAI-6, scores) this anxiety often reduced to baseline over time. When looking at the screening group as a whole, participants of the NLST and NELSON trials had no significant psychological changes over time (6 months to 1 year after screening). However, NELSON trial individuals with high risk perception at baseline have higher distress and, though overall risk perceptions decrease over time, they remain higher than actual risk. In one NELSON trial study, compared to pre-randomization (about half a year before screening), all those screened have worse psychological scores shortly before screening. These scores improve over time, except for those with indeterminate results. Finally, the PLCO trial showed increased health care non-adherence in those with false positive screen result.

The limitations of the literature involve an inadequate number and quality of studies, particularly a lack of good-quality, prospective studies. Internal validity was limited by follow-up in many studies, suggesting that patients in lung cancer screening may have poor adherence to the screening regimen. Additionally, the comparisons in some studies may be misleading. The use of various different measurement tools introduces heterogeneity into the findings of this review. Comparisons between test groups may also be misleading. Lung cancer is one of the most distressing of commonly screened cancer types.<sup>32</sup> I questioned whether screened individuals would suffer greater anxiety from the screening process due to high rates of indeterminate and false-positive results. However, one might expect increased anxiety in volunteers that sign up for a screening intervention, which they might perceive as helpful in preventing mortality from lung cancer, who are assigned to the control arm that does not receive potentially beneficial screening. One study in particular showed better baseline psychological metrics when participants were measured prior to randomization (about six months prior to screening), suggesting that the measurement of psychological status shortly prior to the screening exam may not represent a true baseline measure for those undergoing screening. This is likely due to the anxiety surrounding the test and anticipation of receiving results. Most studies used samples from pre-existing lung screening trials which are inherently limited in external validity, due to participation bias of those being screened (evident by high quality of life, and skewed demographics), and expertise of investigators, clinicians, and equipment involved in evaluating and managing patients.

This review shows evidence that people receiving abnormal screening results experience increased anxiety. Some of the studies in this review show evidence for increased anxiety and distress in individuals who have high risk perceptions. Good quality, consistent evidence for

clinically significant psychological effects for the screening group as a whole is lacking in the current literature. Future research efforts should focus on developing well-designed, prospective, studies that measure long term psychological outcomes to inform patients and providers of this important type of harm inherent in lung cancer screening.

## **Tables and Figures**

### **Appendix A. PICOTSS Criteria: used to outline search strategy**

	Inclusion	Exclusion
Population	Subjects at increased risk for lung cancer. OECD countries.	Confirmed cancer diagnosis
Intervention	Lung cancer screening or surveillance of indeterminate lung findings	Symptomatic diagnostic testing
Comparison	Single cohorts over time, different screening trial arms, screening trial results, population norms	
Outcomes	Psychological harms including depression, anxiety, quality of life, risk perception, suicide	Proxy outcomes
Time of search	Jan 1, 2002 – Dec 31, 2013	
Time for outcomes to appear	Any	None
Settings	Organization for Economic Co-operation and Development (OECD) countries	Non-OECD countries
Study Types	RCT, pro/retrospective cohort, cross-sectional, qualitative. Full text available.	Non-peer reviewed. Non-English language.



## Appendix B. Search Strategy

PubMed: Feb 17, 2014. Found 987

(Lung cancer\*[tw] OR Lung Neoplasms[Mesh] OR lung nodule\*[tw] OR pulmonary nodule\*[tw]) AND (screening\*[tw] OR early diagnosis[tw] OR early detection[tw] OR biops\*[tw] OR surveillance[tw] OR watchful waiting[tw] OR overdiagnos\*[tw] OR over diagnos\*[tw] OR overdetect\*[tw] OR over detect\*[tw] OR insignifican\*[tw]) AND (depress\*[tw] OR distress[tw] OR stress\*[tw] OR worry[tw] OR fear\*[tw] OR anxiet\*[tw] OR quality of life[tw] OR mental health[tw] OR mental disorders[tw] OR psycholog\*[tw] OR psychosocial[tw] OR wellbeing[tw] OR well-being[tw] OR emotion\*[tw] OR false positive\*[tw] OR stigma[tw] OR shame[tw] OR label\*[tw] OR suicid\*[tw])

Limits: Publication Dates From 2002/01/01 to 2013/12/31

CINAHL via EBSCO: Feb 17, 2014. Found 178

(MH "Lung Neoplasm\*" OR "Lung cancer\*" OR "lung nodule\*" OR "pulmonary nodule\*") AND (screening\* OR "early diagnosis" OR "early detection" OR biops\* OR surveillance OR "watchful waiting" OR overdiagnos\* OR "over diagnos\*" OR overdetect\* OR "over detect\*" OR insignifican\*) AND (depress\* OR distress OR stress\* OR worry OR fear\* OR anxiet\* OR "quality of life" OR "mental health" OR "mental disorders" OR psycholog\* OR psychosocial OR "well being" OR emotion\* OR "false positive\*" OR stigma OR shame OR label\* OR suicid\*)

Limits: Publication Date from 2002/01/01-2013/12/31

PsycINFO via EBSCO: Feb 17, 2014. Found 68

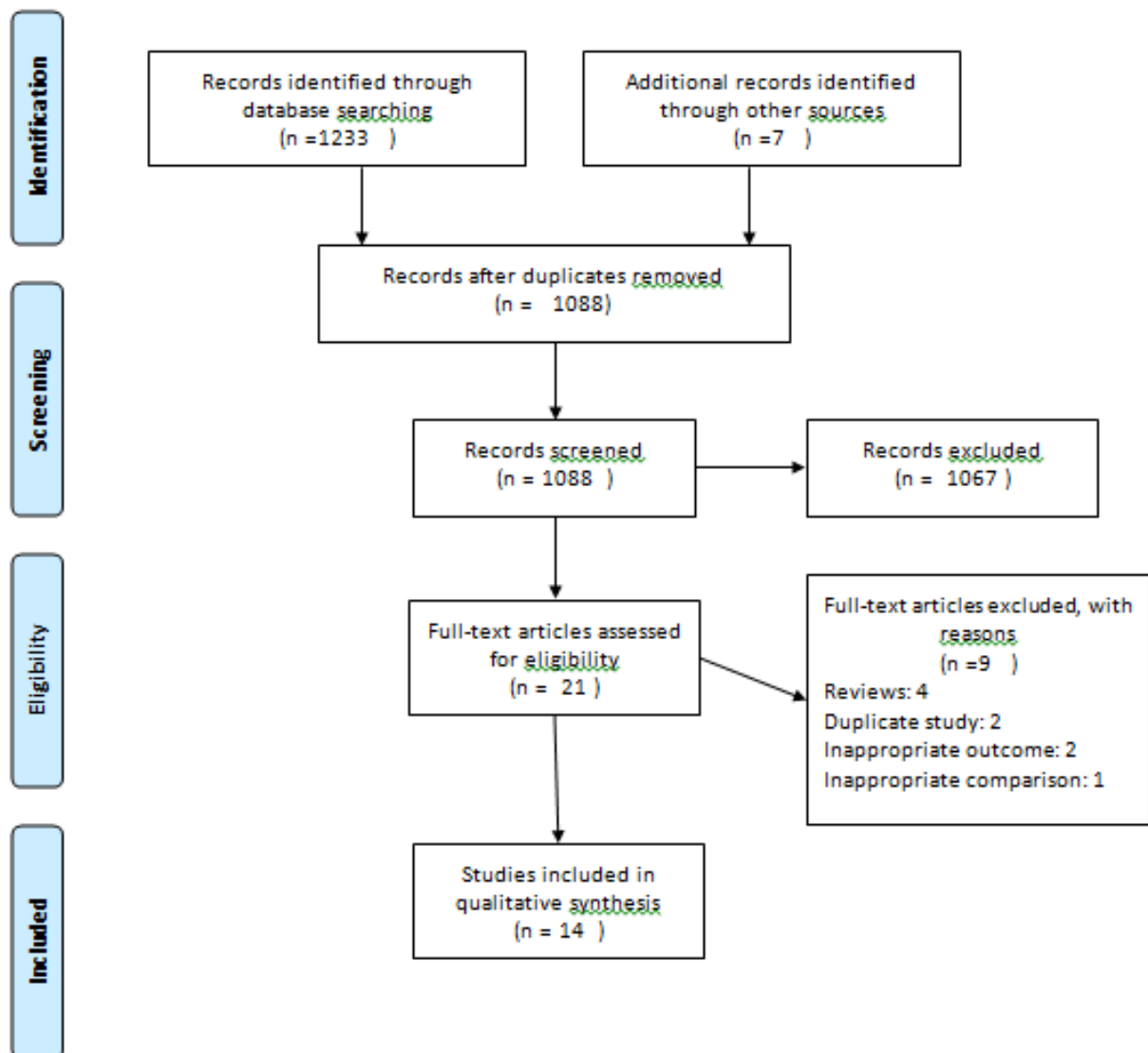
("Lung Neoplasm\*" OR "Lung cancer\*" OR "lung nodule\*" OR "pulmonary nodule\*") AND (screening\* OR "early diagnosis" OR "early detection" OR biops\* OR surveillance OR "watchful waiting" OR overdiagnos\* OR "over diagnos\*" OR overdetect\* OR "over detect\*" OR insignifican\*) AND (depress\* OR distress OR stress\* OR worry OR fear\* OR anxiet\* OR "quality of life" OR "mental health" OR "mental disorders" OR psycholog\* OR psychosocial OR "well being" OR emotion\* OR "false positive\*" OR stigma OR shame OR label\* OR suicid\*)

Limits: Publication Date from 2002/01/01-2013/12/31

## Appendix C. Figure 1: Study Selection<sup>33</sup>



PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 6(6): e1000097. doi:10.1371/journal.pmed1000097

## **Appendix D: U.S. Preventive Services Task Force (USPSTF) Procedure Manual: Criteria for Assessing Internal Validity of Individual Studies<sup>18</sup>**

### Randomized Controlled Trials and Cohort Studies

#### Criteria:

- Initial assembly of comparable groups:
  - For RCTs: adequate randomization, including first concealment and whether potential confounders were distributed equally among groups.
  - For cohort studies: consideration of potential confounders with either restriction or measurement for adjustment in the analysis; consideration of inception cohorts.
- Maintenance of comparable groups (includes attrition, cross-overs, adherence, contamination).
- Important differential loss to follow-up or overall high loss to follow-up.
- Measurements: equal, reliable, and valid (includes masking of outcome assessment).
- Clear definition of interventions.
- All important outcomes considered.
- Analysis: adjustment for potential confounders for cohort studies, or intention to treat analysis for RCTs.

#### Definition of ratings based on above criteria:

- Good: Meets all criteria: Comparable groups are assembled initially and maintained throughout the study (follow-up at least 80 percent); reliable and valid measurement instruments are used and applied equally to the groups; interventions are spelled out clearly; all important outcomes are considered; and appropriate attention to confounders in analysis. In addition, for RCTs, intention to treat analysis is used.
- Fair: Studies will be graded "fair" if any or all of the following problems occur, without the fatal flaws noted in the "poor" category below: Generally comparable groups are assembled initially but some question remains whether some (although not major) differences occurred with follow-up; measurement instruments are acceptable (although not the best) and generally applied equally; some but not all important outcomes are considered; and some but not all potential confounders are accounted for. Intention to treat analysis is done for RCTs.
- Poor: Studies will be graded "poor" if any of the following fatal flaws exists: Groups assembled initially are not close to being comparable or maintained throughout the study; unreliable or invalid measurement instruments are used or not applied at all equally among groups (including not masking outcome assessment); and key confounders are given little or no attention. For RCTs, intention to treat analysis is lacking.

## **Criteria for Assessing External Validity (Generalizability) of Individual Studies<sup>19</sup>**

Study Population: The degree to which the people who were involved as subjects in the study constitute a special population because they were selected from a larger eligible population or were for other reasons unrepresentative of people who are likely to seek or be candidates for the preventive service. The selection has the potential to affect the following:

- Absolute risk: The background rate of outcomes in the study could be greater or less than what might be expected in asymptomatic people because of the inclusion/exclusion criteria, because of non-participation, or for other reasons.
- Harms: The harms observed in the study could be greater or less than what might be expected in asymptomatic people.

The following are features of the study population and the study design that may cause experience in the study to be different from what would be observed in the US primary care population:

- Demographics (age, gender, ethnicity, education, income): The criteria for inclusion/exclusion or non-participation do not encompass the range of people likely to be candidates for the preventive services in the US primary care population.
- Co-morbidities: the frequency of co-morbid conditions in the study population does not represent of the frequency likely to be encountered in people who seek the preventive service in the U.S. primary care population.
- Special inclusion/exclusion criteria: There are other special inclusion/exclusion criteria that make the study population unrepresentative.
- Refusal rate (ratio of included to not-included but eligible participants): The refusal rate among eligible study subjects is high, making the enrollees in the study unrepresentative even of the people eligible for the study.
- Adherence (run-in phase, frequent contact to monitor adherence): The design of the study has features that may make the effect of the intervention in the study greater than it would be in a clinically observed population.
- Stage in natural history of disease; severity of disease: the selection of subjects for the study includes people with at a stage that is earlier or later than would be found in people who are candidates for the preventive service.
- Source, intensity of recruitment: The sources for recruiting subjects for the study and/or the effort and intensity of recruitment may distort the characteristics of the study subjects in ways that could increase the effect of the intervention as it is observed in the study.

#### Situation:

The degree to which the clinical experience in the situation in which the study was conducted is likely to be reproduced in other settings

- Healthcare system: The clinical experience in the system in which the study was conducted is not likely to be the same as experience in other systems because, for example, the system provides essential services for free when these services are only available at a high cost in other systems.
- Country: The clinical experience in the country in which the study was conducted is not likely to be the same as in the U.S. because, for example, services available in the U.S. are not widely available in the other country of study conduct or vice versa.
- Selection of participating centers: The clinical experience in which the study was conducted is not likely to be same as in offices/hospitals/settings in which the service will be delivered to the U.S. primary care population because, for example, the centers have ancillary services not available generally.

- Time, effort, and system cost for the intervention: The time, effort, and cost to develop the service in the study is more than would be available outside the study setting.

#### Providers:

The degree to which the providers in the study have the skills and expertise likely to be available in general settings

- Training to implement the intervention: The intervention in the study was done after giving providers special training not likely to be available or required in U.S. primary care settings.
- Expertise, skill to implement intervention: The providers included in the study had expertise and/or skills at a level that is higher than the level likely to be encountered in typical settings.
- Ancillary providers: The study intervention relied on ancillary providers who are not likely to be available in typical settings.

#### Global Rating of External Validity (Generalizability):

External validity is rated "good" if:

- The study differs minimally from the US primary care population/situation/providers and only in ways that are unlikely to affect the outcome; it is highly probable (>90%) that the clinical experience with the intervention observed in the study will be attained in the US primary care setting.

External validity is rated "fair" if:

- The study differs from the US primary care population/situation/providers in a few ways that have the potential to affect the outcome in a clinically important way; it is only moderately probable (50%-89%) that the clinical experience with the intervention in the study will be attained in the US primary care setting.

External validity is rated "poor" if:

- The study differs from the US primary care population/ situation/ providers in many way that have a high likelihood of affecting the clinical outcomes; the probability is low (<50%) that the clinical experience with the intervention observed in the study will be attained in the US primary care setting.

#### **Key questions for appraising quality of qualitative research studies<sup>34</sup>:**

- Was an appropriate sample used for the research question?
- Was the data collected appropriately?
- Was the data analyzed appropriately?
- Are the results of this study relevant to my own setting?
- Are potential ethical issues addressed?
- Is it clear what the researchers did in the study?

**Appendix D. Table a. Strength of evidence rating from USPSTF Procedure Manual** <sup>35</sup>

Level of Certainty	Description
High	<p>The available evidence usually includes consistent results from well-designed, well-conducted studies in representative primary care populations. These studies assess the effects of the preventive service on health outcomes. This conclusion is therefore unlikely to be strongly affected by the results of future studies.</p>
Moderate	<p>The available evidence is sufficient to determine the effects of the preventive service on health outcomes, but confidence in the estimate is constrained by factors such as:</p> <ul style="list-style-type: none"> <li>• The number, size, or quality of individual studies.</li> <li>• Inconsistency of findings across individual studies.</li> <li>• Limited generalizability of findings to routine primary care practice.</li> <li>• Lack of coherence in the chain of evidence.</li> </ul> <p>As more information becomes available, the magnitude or direction of the observed effect could change, and this change may be large enough to alter the conclusion.</p>
Low	<p>The available evidence is insufficient to assess effects on health outcomes. Evidence is insufficient because of:</p> <ul style="list-style-type: none"> <li>• The limited number or size of studies.</li> <li>• Important flaws in study design or methods.</li> <li>• Inconsistency of findings across individual studies</li> <li>• Gaps in the chain of evidence;</li> <li>• Findings not generalizable to routine primary care practice</li> <li>• A lack of information on important health outcomes.</li> </ul> <p>More information may allow an estimation of effects on health outcomes.</p>

Appendix E. Table A: Category 1 Studies

Author, Year	Design, N	Setting, Population Characteristics	Comparisons, Measurement Intervals	Results, Instruments	Internal Validity	External Validity
Paris et al, 2010 <sup>10</sup>	Prospective Cohort, 832	Consecutive sample from French Asbestos Post-Exposure Survey, 2005. Female: 7.7%, Age: 62, Current Smoker: 9.1%, Former Smoker: 45.1%, Asbestos Exposure-Light: 11.3%, Moderate: 40%, Heavy: 26%, Unknown: 22.7%	By exposure categories vs. control (unknown exposure). Baseline and 6 months after screen.	<ul style="list-style-type: none"> <li>- Increased abnormal PCQ scores at T2 vs. T1 (32.6% vs. 20.5%). Increased among all groups (even normal screen) at T2 compared to baseline.</li> <li>- Greater increase with abnormal screen results.</li> <li>- Patients with pleural plaques had higher scores at T2 than other groups at T2</li> <li>- 19% of those with normal T1 score had abnormal T2 Score</li> </ul>	Fair	Poor
Vierikko et al, 2009 <sup>21</sup>	Prospective Cohort, 457	Finnish workers with asbestos exposure. Group 1 had prior asbestos screening, asymptomatic with no disease. Group 2 and 3 from clinic patients with pulmonary disease. Age 64.7, Married: 83.8%, Pack years: 17.1, Current Smoker: 17.9%, Former Smoker: 59.5%, Asbestos years: 19.2, Dyspnea: 40.1%	By screen result (negative vs. false positive). Baseline and 1 year after screen.	<ul style="list-style-type: none"> <li>- Health anxiety questionnaire scores lower after screening in both negative and false positive groups</li> <li>- Health anxiety scores higher in the FP group vs. negative group.</li> <li>- Perceived cancer risk (33.6%) higher than in other studies.</li> </ul>	Poor	Poor

Appendix E. Table B: Category 2 Studies

Author, Year	Design, N	Setting, Population Characteristics	Comparisons, Measurement Intervals	Results, Instruments	Internal Validity	External Validity
Mazzone et al, 2013 <sup>22</sup>	Prospective cohort, 1424	Cleveland Clinic Screening Study. Age: 60.1, Female: 54.3%, Current smoker: 51%,	One cohort. Baseline questionnaire, and every 6 months for 2 years.	<ul style="list-style-type: none"> <li>- 25 (out of 711 in screen group) Patients notified of nodules. EQ-5D lower after notification, no other metrics changed. 14 /25 were NLST eligible.</li> <li>- Patients notified of nodule had higher imaging use at 6-months (25.5% vs. 9.3%), no diff in other health care use.</li> </ul>	Fair	Poor
Slatore et al, 2013 <sup>23</sup>	Qualitative, Cross-Sectional, 19	Veteran's Affairs. Asymptomatic with pulmonary nodule, under surveillance. Age: 66, Female: 5%, White: 94%, Current Smoker: 21%, High school or less: 39%	No comparison. Single interview.	<ul style="list-style-type: none"> <li>- Patients rarely understood follow up plans.</li> <li>- Most perceived nodule to be dangerous, level of care inadequate for their perceived severity.</li> <li>- Variable degrees of distress response</li> <li>- Most patients know nodule is related to cancer and experience at least mild distress with diagnosis.</li> </ul>	Good	Poor
Wiener et al, 2012 <sup>24</sup>	Qualitative, Cross-Sectional, 22	Patients with pulmonary nodule from an urban-underserved or rural referral center. Age: 60.7, Female: 86%, White: 77%, Current or Former Smoker: 68%, Mode of Discovery: symptomatic workup: 18%, Incidental finding: 82%, lung cancer screening: 0%	No comparison. Single interview.	<ul style="list-style-type: none"> <li>- Almost all initially assume nodules are cancer.</li> <li>- Some patients experience confusion and stress that lasts for months when not adequately informed about the cancer risk of the nodule.</li> <li>- Anxiety and frustration over concerns not being fully addressed and the lack of attention given to the nodule, sometimes leading to poor adherence to further evaluation</li> <li>- It is helpful when clinicians use lay terminology, show CT images, and quantify cancer risk.</li> </ul>	Good	Fair



Appendix E. Table C: Category 3 Studies

Author, Year	Design, N	Setting, Population Characteristics	Comparisons, Measurement Intervals	Results, Instruments	Internal Validity	External Validity
Park et al, 2013 <sup>36</sup>	Prospective cohort, 430	Consecutively enrolled NLST participants from 8 sites, Dec 2003 to Mar 2004. Age, 61.0, Female: 44.4%, White: 91.9%, Current smokers: 49.3%, Post-highschool: ~61%, Pack-years: 55	One cohort. Before initial screen and before 1 year follow up.	- Risk perceptions and cognitive and emotional determinants of behavior change (custom questionnaire) did not change significantly over time, or by screening result. - Changes in risk perceptions not associated with changes in smoking status at 1-year follow up. - Current vs. former smokers had higher risk perceptions for lung cancer and other smoking-related diseases.	Fair	Fair
Aggestrup et al, 2012 <sup>26</sup>	Randomized Control Trial, 3701	DCLST participants. Age: 57, Female: 44%, Current smoker: 76%, Pack-years: 36	Screen vs. control arm. Before screen and after screening round.	- At follow up both groups had increased anxiety, dejection, self-blame and behavior scores(COS), no difference in mean increase between groups.	Fair	Fair
van den Bergh et al, 2010 <sup>27</sup>	Randomized Control Trial, 630	NELSON Trial, Consecutive enrollees from two centers. Female: 53%, Age: 57.8, >High School Education: 27.7%, Current Smoker: 54.6, Pack-years: 40.1.	Screen result Pre-randomization, just prior to screen, 1 week after screen, 2 months after screen.	- EQ-5D, STAI-6, & IES worse at T1 vs. T0 for both groups (statistically) - No clinically relevant changes over time - Distress and anxiety better at T2 vs. T1 overall - No change in EuroQol-5 and STAI-6 between T0, T1, T2 for whole sample - For indeterminate result, EQ-5D and distress worse at T3 vs. T2 (only clinically relevant change) and vs. T0.	Fair	Fair

Appendix E. Table C: Category 3 Studies continued.

Author, Year	Design, N	Setting, Population Characteristics	Comparisons, Measurement Intervals	Results, Instruments	Internal Validity	External Validity
Bunge et al, 2008 <sup>29</sup>	Prospective Cohort, 288	NELSON trial. Age: 60.3, Female: 48.1%, Current smoker: 74.7%	By cancer risk perception (high vs. low). Day 1 before screen and 6 months after.	<ul style="list-style-type: none"> <li>- Those with high risk perception at baseline (14.6%) had higher median distress and mental component of SF-12.</li> <li>- All groups had lower IES at 6mo</li> <li>- At 6 months fewer perceived risk as high (10.5%)</li> </ul>	Good	Fair
Byrne et al, 2008 <sup>37</sup>	Prospective Cohort, 393	Pittsburgh Lung Screening Trial. Age: 60.2, Female: 49.3% White: 94.5%, Years smoked: 40.8, Current Smoker: 59%, College Grad: 32%	By screen results: negative, probably benign, or suspicious. Prior to screen, after results, 6 months after, 12 months after.	<ul style="list-style-type: none"> <li>- State anxiety (STAI-6) and fear of cancer score increased after non-negative results. These decreased by 12 months after screening.</li> <li>- Negative screening results had stable fear of cancer and STAI-6 over time.</li> <li>- Lower anxiety among higher education and married.</li> <li>- Higher anxiety among smokers.</li> <li>- Baseline cancer risk perceptions are high (18%) and remain higher than reality after screening, regardless of result.</li> <li>- Risk Perceptions fall to 13% with negative screen, no change with non-negative screen (actual risk is &lt;1%)</li> </ul>	Good	Fair
van den Bergh et al, 2008 <sup>28</sup>	Prospective Cohort, 336	NELSON Trial. Consecutive enrollees from two centers. Female: 49.1%, Age: 60.3, High school or greater: 19.4%, Current smoker: 74.7%	One cohort. Sub-grouped by demographics. 1 week before, one day after, 6 months after baseline screen.	<ul style="list-style-type: none"> <li>- SF-12, EQ-5D, STAI-6, IES similar to population norm at baseline, no clinically significant difference over time.</li> <li>- Discomfort: 46.4% have discomfort awaiting results, 50.5% dread results.</li> </ul>	Fair	Poor
Ford et al, 2003 <sup>31</sup>	Retro-spective cohort, 4705	PLCO participants from Detroit site. FP: 1137, Neg: 3568, True Pos excluded. Age: 62.3, Female: 55%, White: 84.2%, Post-High school: 69.3%, Current smoker: 14.4%, Former smoker: 48.7%	By screen result (negative vs. false positive). Baseline screen and yearly follow up.	<ul style="list-style-type: none"> <li>- &gt;50% increase in non-adherence among FP vs. Neg</li> <li>- Increased non-adherence among African Americans (OR: 1.5), women vs. men (OR: 1.4), current smokers vs. never smokers (OR=1.4), older, lower education</li> <li>- FP cases were older, more male, more current smokers</li> </ul>	Good	Fair

## Patient Perceptions of Benefits, Harms, and Risks of Lung Cancer Screening

### Abstract

**Introduction:** Patients eligible for participation in recently recommended lung cancer screening programs may be poorly informed about the benefits and harms of screening. We conducted a preliminary investigation of risk perceptions as well as perceptions of potential benefits and harms of lung cancer screening, among patients at increased risk for lung cancer.

**Methods:** I performed a cross-sectional study of general medicine outpatients at increased risk of lung cancer (50-80 years old, at least 30 pack-year smoking history). I surveyed participants about the following topics: perceived effects of screening on smoking cessation, overall knowledge of lung cancer screening, perceptions of lung cancer risk, and reasons why people would want to get screened. I collected demographic and smoking history information necessary to use a lung cancer risk calculator, in order to compare calculated risk estimates with study participants' perceived risk.

**Results:** 24 eligible respondents were recruited. The knowledge accuracy on the 5 NLST-based questions was 17%. Average risk perception of getting cancer, and dying from cancer with and without screening over the next six years was 26%, 17.5%, and 25.1%, respectively. The most common reason cited to participate in screening was early detection allowing early treatment, and the most common reason not to get screened was fear or anxiety of the results, followed by financial concerns.

**Conclusion:** Patients eligible for lung cancer screening overestimate their risk of getting, and dying from lung cancer. People at increased risk of lung cancer underestimate the potential harms and overestimate potential benefits of screening.

## **Introduction**

Each year an estimated 158,000 premature deaths in the U.S. are attributed to lung cancer.<sup>38</sup> Overall, smoking is responsible for around 440,000 premature deaths, 5 million potential life years lost, and estimated productivity losses valued around \$96.8 billion each year.<sup>39</sup> Smoking is a major cause of morbidity as well; the CDC estimated in the year 2000, 8.6 million people suffered from 12.7 million smoking related diseases in the U.S.<sup>40</sup>

Due to the high disease burden and aggressive nature of lung cancer, there has been considerable effort to detect and treat cancer at earlier stages through screening programs. The largest and perhaps most significant study of lung cancer screening, the NLST, included over 50,000 people at increased risk of lung cancer (55-74 year-olds, with at least 30 pack years, and if a former smoker, had not quit more than 15 years ago).<sup>7</sup> The trial showed a 20% relative decrease in lung cancer mortality in those screened with LDCT vs. chest x-rays.<sup>7</sup> These results were important considerations in the recent Grade B recommendation from the USPSTF for LDCT in screening patients at increased risk for lung cancer. This recommendation was for people that meet the same NLST eligibility criteria, but expanded the age range to 55-80 year olds.<sup>8</sup> Several other groups have published similar guidelines for lung cancer screening eligibility (Appendix 1).

There are many potential benefits of LDCT screening beyond a 20% relative lung cancer mortality reduction.<sup>7</sup> There may also be benefits in exposing individuals to the health care system, one of the most significant may be in increasing smoking cessation rates.<sup>41-43</sup> Additionally, patients may be reassured by the screening process relieving anxiety about the possibility of having cancer.<sup>21,27</sup>

Though the USPSTF's review shows a net benefit in decreased lung cancer mortality, there are also substantial harms. In the NLST, 96.4% of positive screens were false positives resulting in many follow up diagnostic tests, additional radiation exposure, and invasive biopsies, bronchoscopies, and thoracotomies for individuals who did not have lung cancer.<sup>7</sup> There is increased radiation exposure, time lost to screening, opportunity costs of health care resources spent, and overdiagnosis.<sup>44</sup> Additionally, participants with abnormal screens experience adverse psychosocial effects and simply being invited to participate in cancer screening may also have negative psychological consequences for patients, as demonstrated in the preceding review.<sup>22-24,27-30,45</sup>

Though the relative risk reductions are assuring, using the NLST mortality data, we calculate an absolute risk reduction of around 0.5% for the study sample as a whole and that 320 people would need to be screened to prolong one life. The absolute risk reduction is highly variable, but can be estimated on an individual basis using a calculator from the Memorial Sloan Kettering Cancer Center based on smoking history, age, gender, and asbestos exposure.<sup>46</sup> Using various risk factors, one study divided the NLST group into quintiles to show that further stratification of risk for redefining eligibility for screening could increase the precision; Kovalchik showed that screening the 60% of the sample at highest risk would have prevented 88% of all the lung cancer deaths prevented in the NLST.<sup>47</sup>

In general, patients in lung cancer screening programs tend to overestimate their risk of lung cancer and, regardless of results of screening, surveys from before and after screening show long term perceptions of lung cancer risk remain elevated.<sup>25</sup> Few past studies have investigated patient perceptions regarding their personal risk for lung cancer and their perceived benefit from screening with CT. Furthermore, patients' understanding of the various benefits and harms they

may experience from screening may be influenced by anxiety surrounding lung cancer and their long term smoking exposure.<sup>9</sup> This is important particularly in relation to patients' potential benefits based on their underlying risk for developing clinically meaningful lung cancer.

This study sought to investigate whether patients understood the potential benefits and harms of LDCT screening. We also questioned whether patients would overestimate their personal cancer risk and misinterpret the risks involved in LDCT screening. We proposed to determine if our participants would neglect psychological harms and overall effect on quality of life of participating in lung cancer screening and wondered if there may be an association between education level and inaccurate risk, benefit, and harm perceptions. The original research presented in this paper was designed to determine to what extent these misconceptions exist by assessing patient conceptions of screening and comparing them with estimates of benefits and harms derived from the NLST data. The responses will be important in highlighting misunderstandings about screening and cancer risk. This pilot data will also be useful in designing future surveys and panel sessions that will be necessary to construct tailored decision aids and counseling services for patients eligible for lung cancer screening.

## **Methods**

**Study Design.** The study design was a cross-sectional interview questionnaire given by the author to patients that were eligible (or near-eligible) for lung cancer screening based on USPSTF recommendations (Appendix 1).

**Subjects.** I recruited patients ages 50-80 with 30 pack-year smoking history from a general-medicine outpatient clinic in a university hospital setting. I reviewed clinic appointment

schedules for potentially eligible participants based on age and smoking status; the electronic health record used would indicate only if the patient was a current or former smoker. I spent 2-3 out of 5 weekdays recruiting subjects; these days were variable and based on my availability (a convenience sample), and potential participants volunteered for the study in order of attendance to clinic and depending on providers' availability, preference, and schedule. Participants were offered no compensation, beyond general information about lung cancer screening. Participants were not required to be clinic patients; I also invited accompanying family or friends that met eligibility criteria.

**Measurements.** We developed a survey to measure desired study outcomes (Appendix 2). Questions were designed to determine participant eligibility based on age, smoking history, and other risk factors (items 1-8, 17, 18, 28). The participant was asked about their clinic history and if they had ever been counselled by a physician about lung cancer screening; if they had ever had a CT scan, or had ever been screened for lung cancer, there were additional questions to determine results of these tests (items 9-13). For current smokers, questionnaire items inquired about perceived effects of screening participation on smoking cessation (items 14-16). Five multiple choice questions were designed to assess the participants' perceptions of the potential benefit and harm of screening (items 19-23).

Specifically, participants were asked to estimate their risk of developing lung cancer, and their risk of dying from lung cancer, both with and without screening, over a six year period (items 24-26). These risk predictions were later compared to risk estimates using a calculator from the Memorial Sloan Kettering Cancer Center.<sup>46</sup> This risk calculator used age, gender, smoking years and cigarettes per day, quit status, and asbestos exposure to estimate risk of being diagnosed with and dying from lung cancer over the next six years, with and without screening.<sup>46</sup>

To determine relative risk perceptions, one question asked the participant to rate their risk relative to others at risk for lung cancer (item 27).

Two open-ended questions about why people should and should not undergo screening concluded the interview (items 29, 30). These questions were placed at the end of the survey to determine whether patients would consider, without being prompted, screening associated harms such as false positives and follow up invasive testing. Once patients finished responding, I provided probes about possible reasons one would not want to be screened and recorded whether participants agreed with these reasons or had additional opinions. These included issues such as finances, anxiety about testing and cancer, and access to a health care provider. Demographic information was collected, including height, weight, gender, race, education, and health literacy level (items 31-35).

Prior to beginning the survey, participants were given basic information about the lung cancer screening process. I ensured that the participant understood the definition of screening as a preventive service for asymptomatic individuals with a smoking history, using CT scans to look at the lungs. Participants were asked about their familiarity with a CT scan, and this mode of imaging was explained briefly when necessary. At the conclusion of the interview the participant was debriefed about the answers to the knowledge-based questions using NLST outcomes data. The participant's risk perceptions were discussed based on Kovalchik's risk quintiles, and finally concerns about potential risks of screening were addressed.<sup>47</sup> After the survey, I gave participants information about risk and provided basic counseling about lung cancer screening.



**Analysis.** The responses to knowledge-based questions (items 19-23), were graded and accuracy for each item was scored. I calculated mean responses to absolute risk perception items (Items 24-26) and compared these to mean calculated risks. Individual responses to knowledge-based and risk-perception items (items 19-27 in questionnaire), total number of correct knowledge based items, as well as comparative risk were assessed with chi-squared test for associations by education level. Due to limited sample size, self-reported education (item 26) was dichotomized into those with high school education or less, and those with any education beyond high school. Kruskal-Wallis tests were used for associations between absolute risk perceptions (items 24-26) and education. Data analyses were performed using Stata (Release 13; StataCorp LP, College Station, TX, USA).

## **Results:**

**Participation.** Of the 234 patients marked as smokers in the medical record, I approached 79 patients over ten clinic mornings. Overall, 16 declined, 38 were ineligible, 1 was unable to complete the survey, and 24 were interviewed for a participation rate of 30.3%. Of the 234 clinic patients marked as smokers by the electronic medical record, 44.4% were current smokers. One interview was given via telephone to an interested patient who was missed in clinic and one interview was given to an eligible family member (non-patient) of an ineligible clinic patient.

**Sample characteristics.** The sample consisted of 24 respondents that met our eligibility criteria. The majority of respondents (19/24) met USPSTF screening guideline eligibility; two were young (51 and 54), but will be eligible once they turn 55, and three had quit over 15 years

ago (16, 22, and 33 years). The sample is summarized as follows: female: 50%, average age: 64.6 years, current smoker: 33%, pack-years:  $43 \pm 15.1$  years, white: 33%, COPD or emphysema: 71%, asbestos exposure: 50%, education greater than high school 37% (Table 1).

**Knowledge of benefit & harm.** On the five multiple choice questions regarding NLST trial results, the respondents averaged 17% accuracy. The question with the most correct responses was item 13, which asked: about how many individuals would receive an abnormal screening result (42% correct)? The question with the most incorrect responses was item 14, which asked what the false positive rate would be in those receiving abnormal screen results (0% correct) (Table 2).

The multiple-choice, knowledge-based questions had interval valued answer choices and so their responses may be summarized as follows: 83% overestimated the number who would have their lives prolonged, 63% underestimated the number of invasive procedures that would not eventually find cancer, 50% underestimated the proportion whom would have an abnormal screen result, 100% underestimated the proportion of false positive screen results, and 88% overestimated the benefit in absolute mortality reduction.

Quantitative analysis of knowledge-based questions showed statistically significant (at 5% alpha) association of higher educated respondents answering item 19 (how many screened would have their lives prolonged?) correctly more frequently than lower educated respondents ( $p=0.025$ ). However, a Bonferroni adjustment for these tests run on each of the 5 knowledge based questions would change a necessary alpha to 0.01, making this association no longer statistically significant. No other individual items showed statistically significant variation in

accuracy by education level. The total number of correct knowledge-based questions did not vary by education level.

**Risk Perception.** When asked to estimate their personal risk of being diagnosed with lung cancer over the next six years, respondents averaged 26% probability (range from 0-80%). Respondents' estimation of their risk of dying from lung cancer if they were in a screening program averaged 17.5% (range from 0-80%), and their estimated risk of dying from lung cancer without screening averaged 25.1% (range from 0-80%).

Of the 22 respondents who estimated their risk of dying from lung cancer over the next six years with and without screening, respectively, seven and six participants estimated a 0% chance. All other respondents over-estimated their risks of dying from lung cancer over the next six years compared with the results from the Memorial Sloan Kettering Calculator.<sup>46</sup> Of the 15 respondents who gave non-zero estimates of their risk of dying from lung cancer given participation in screening, the average response was 24.6%; the average estimate was 1.53% using the risk calculator. Of the 16 respondents who gave non-zero estimates of their risk of dying from lung cancer over the next six years without screening, the average response was 34.5%; the average estimate was 2.03% using the risk calculator. This group overestimated their risk of dying from lung cancer by 23% and 32% points, and in relative terms, this group's perceived risk was 16 and 17 times the risk given by the calculator estimate, with and without participation in screening, respectively. The predicted effects of LDCT screening on relative reductions in lung cancer mortality were 28.7% for participant responses and 24.6% for calculated estimates.

When asked to compare their risk of getting lung cancer to the risk of other people at increased risk for lung cancer, 65% (15/23) believed their risk to be the same or less than others (Table 3). Individuals estimated absolute and comparative risk perceptions did not vary by education level.

The free-response questions about why individuals would or would not want to get screened for lung cancer reached saturation over the course of multiple interview days. The most common theme for why individuals would want to get screened was early detection leading to early treatment and better outcomes; 16 of the 24 respondents spontaneously (without any probe or structured lead-in) generated this response. Five respondents brought up anxiety or curiosity about having cancer, and the desire to know the diagnosis as reasons to get screened. When asked why someone would not want to get screened, the majority mentioned anxiety or fear surrounding the test and receiving results (17 out of 24, 4 of these agreed after being probed if this could be a concern). Most respondents had little to say in response to this question, and so a standardized probe used to ask participants if they thought that individuals might have certain concerns (financial, anxiety, access, etc.) elicited additional responses. Of the 24 respondents, 12 mentioned financial concerns (9 of these responses were after probe), and 9 respondents mentioned access or difficulty getting to the doctor or getting the tests (4 after probe).

**Screening effect on smoking cessation.** Eight current smokers participated in the study. These individuals all reported they would be just as likely or more likely to quit smoking if they participated in screening. Participants were also asked about their likelihood to quit if they received a normal, or an abnormal screening result. If they received normal results, all would also be just as likely or more likely to quit. If they received abnormal screening results, only one

respondent answered they would be less likely to quit, all others would be just as likely or more likely to quit smoking (Table 4).

### **Discussion:**

The goal of this study was to examine the risk perceptions of those eligible or near-eligible for lung cancer screening by LDCT, and to assess their level of understanding regarding the potential benefits and harms of screening. This relatively small (n=24) convenience sample study suggests that this population may lack an understanding about the potential benefits and harms of screening, and may overestimate their potential risk for developing and dying from lung cancer.

On knowledge-based questions, respondents performed particularly poorly when asked to estimate how many of those receiving abnormal screen results would not have cancer (false positives); none of the 24 respondents answered this question correctly suggesting that participants overestimate the accuracy of LDCT screening. The question answered correctly most often regarded the percentage of those screened who would have abnormal results (42% correct). I believe this item was answered correctly more often than others because it used wide ranges (particularly for the correct response), and the correct response was not one of the extreme choices (as it was in the other questions). Also, individuals overestimate their absolute risk of cancer, and so are likely to consider the possibility of getting abnormal screen results. Because most answer choices were presented in ordinal fashion, I concluded that respondents overestimate the diagnostic accuracy and mortality benefit of lung cancer screening with LDCT and underestimate the potential harms of screening.

**Knowledge of screening & risk perception.** Overall, our study sample performed poorly on knowledge based questions (17% accuracy overall). The participants in our study all underestimated the rate of false positives in LDCT screening. Other studies show that patients have high expectations for both sensitivity and specificity of the screening CT exams: 92% disagreed with the statement, “If a test says I do NOT have lung cancer when I DO, that is OK with me,” and 84% disagree with the statement, “If a test says I may have lung cancer when I do not that is OK with me.”<sup>48</sup> The rate of abnormal, and follow up false positive screen results is an important factor for those considering screening; the preceding review of psychological effects of screening has shown that many patients experience psychological distress in response to receiving indeterminate results, or undergoing surveillance for possibly pre-cancerous lesions. As Kovalchik has shown, stratifying NLST participants into risk quintiles may improve the balance of benefits and harms: 60% of NLST participants at highest risk for lung cancer mortality make up 88% of all lung cancer deaths prevented by screening.<sup>47</sup> This evidence is promising in that we may be able to target screening in those who are at highest risk, and prevent possible harmful effects of screening in those who may benefit less.

The study sample overestimated their risk of being diagnosed with, and dying from, lung cancer. Results of other studies are concordant with the high absolute risk perceptions prevalent among the sample in this survey. Among participants in one CT-trial, 64% and 76% perceived high absolute and comparative lung cancer risk, respectively, and 94% reported concern over developing lung cancer.<sup>48</sup> Our study sample differs from these results on comparative risk, however; in our sample risk compared to other smokers was rated as average, or as less than average.

Through my experience interacting with patients in interviews, those eligible for screening know little about LDCT and lung cancer screening in general, but appear highly interested in the concept as a means of early detection and improved treatment outcomes. Other literature has shown that though awareness of CT screening may be low even in people who are close to lung cancer patients (77% unaware of CT screening), there is high interest upon being informed of screening: 67% were at least somewhat interested in being screened and 62% indicated they would likely enroll in a lung cancer screening program if it were free.<sup>49</sup> There are many factors influencing participation in lung cancer screening, and these may have significant implications for the broad implementation of screening and properly informing those eligible about the screening process. In a survey of Dutch patients given information and a questionnaire about lung cancer and CT screening prior to participation in the NELSON trial, there were important differences in the lung cancer knowledge and risk perceptions between participants who enrolled in the trial and those who opted out. Overall, knowledge about screening was low in both groups (around one-third responded "do not know" and about 40% underestimated the rate of indeterminate, or abnormal/positive findings).<sup>50</sup> Screening participants vs. non-participants answered questions about lung cancer screening more accurately (51.4% vs. 38.1%) and had more knowledge about the trial and lung cancer overall (72.7% vs. 53.6%).<sup>50</sup> More screening participants showed a positive attitude toward screening than non-participants (98.7% vs. 63.8%) and participants more often reported high lung cancer risk perceptions (14.4% vs. 6.5%).<sup>50</sup> This is important in considering generalizability of the lung cancer screening trial results to a population which may have a much less informed position about the screening process than those participating in the trials. In general, all patients are not likely to understand the procedural details and risks involved in lung cancer screening.

**To screen, or not to screen?** The conversational portion of the interview elicited few unique responses and very limited interactive dialogue, suggesting that patients who are eligible for lung cancer screening have not seriously considered the details of the screening process. Only one participant acknowledged having actively researched lung cancer screening with LDCT; this patient was well-educated, answered knowledge-based questions more accurately (closer on an ordinal scale), and had reasonable personal risk perceptions. It may be that as patients are exposed to the limitations involved in the screening process they may be more skeptical and more prone to consider their personal situation, rather than deferring to guidelines and automatically participating.

The most common reasons to participate among those considering the NELSON trial was an advantage in detecting lung cancer earlier (80%) while the most common reason not to participate was the amount of effort involved (~50%).<sup>50</sup> These responses rates were similar in this study; 67% mentioned benefits of early detection, and 38% mentioned difficulty with access or getting to the tests. A more common concern in my study sample was fear and anxiety (71%) and financial costs of screening tests (50%), though the NELSON trial took place in a nationalized health system, likely making financial costs a less significant concern

**Cessation.** In our small sample of current smokers, hypothetical participation in a screening program did not seem to have a negative effect on respondents' intentions to quit smoking, and 50% of respondents reported that screening would make them more likely to quit.

There is mixed evidence in the literature regarding screening's effect on smoking cessation. Overall, quit rates among the general population of U.S. smokers are lower in older vs. younger smokers; of those 50-64 years old, annual quit rates are around 65% for any serious



attempt, 35% for at least one day, and 5% for at least 6 months of cessation.<sup>51</sup> Several studies have reported smoking cessation rates as well as attitudes regarding cessation among lung cancer screening trial participants. In one study, 74% of screening participants report increased motivation to quit and 49% reported either having reduced or quit smoking after screening.<sup>52</sup> In the Pittsburgh Lung Screening Study, 58.5% reported any quit attempt and 27.2% reported a quit interval greater than 30 days.<sup>41</sup> Among a sample NLST participants, 31.5% had greater readiness to quit after the first screening round.<sup>53</sup> However, in the Danish Lung Cancer Screening Trial there was no difference in quit rates among current smokers and no difference in relapse rates for former smokers in screen vs. control arm one year post screen.<sup>54</sup> Beyond participation in screening, the screen result may have some effect on cessation rates as well. Abnormal results can lead to increased cessation readiness and higher quit rates in current smokers and a lower relapse rate in former smokers, whereas negative results can lead to less readiness to stop smoking.<sup>41,53,54</sup> Despite possible negative or positive psychological effects of screening on cessation, CT screening may represent a clinical opportunity to intervene and promote smoking cessation through creating a clinical relationship and providing the patient with therapeutic opportunities.<sup>41,53</sup> Ideally though, smoking cessation counselling should be done in a primary care setting; it is unfortunate that an intervention as intense as LDCT screening could inadvertently be used as a method to motivate patients to stop smoking.

The potential to intervene and improve cessation rates may be a very important aspect of screening programs, as cessation will not only lower lung cancer risk, but improve health status in many other body systems as well. The dramatic effect of variable cessation rates is seen in a cost-effectiveness analysis of LDCT screening. Hypothetically, if screening could double participants' background cessation rate from 3% to 6%, it would cost around \$40,000/QALY

(women) to \$73,000 (men); however, if screening halved the cessation rate to 1.5% it would cost \$880,000/QALY (men) to >\$1 million/QALY (women).<sup>55</sup>

**Moving forward & making better choices.** Traditional medical practice may be thought of as illness-oriented medicine, which involves searching for a distinct fault, diagnosing this fault as disease, and then systematically treating the disease to cure.<sup>56</sup> LDCT screening practice seems to fall into this doctrine. Another mode of medical thinking is patient-centered medicine which involves making an overall diagnosis by capturing everything a physician knows about the patient and considering each patient as a unique human being.<sup>56</sup>

One aspect of patient-centered medicine is shared decision making, in which patients take an active role with clinicians in understanding their health care options. This process can facilitate patient autonomy, improve patient-clinician relationships, and improve patient knowledge in order to give a more realistic perspective about the screening process and what a patient might expect to experience.<sup>57</sup> Ultimately, decisions should be based on the outcomes patients find most important; these are often not intermediate outcomes like blood pressure or cancer cell-type which may affect management but are not necessarily integral to the patient's experience.<sup>58</sup>

Though certain patients may be interested and may benefit from shared-decision making, certain medical concepts, such as the risk of harms in screening, may be difficult to comprehend. Patients with low literacy and numeracy have particular difficulty, but even well-educated patients experience confusion due to clinicians' use of ambiguous terminology when discussing risk.<sup>59</sup>

According to Sheridan, to properly engage patients in decision making a clinician can ensure the patient<sup>59</sup>:

1. Understands the risk or seriousness of the disease or condition to be prevented.
2. Understands the preventive service, including the risks, benefits, alternatives, and uncertainties
3. Has weighed his or her values regarding potential benefits and harms associated with the service

The results of this study will be used to plan further investigation of patient perceptions of risk and the screening process. This information will be important to better engage patients through these three guidelines and improve understanding of their options for screening, and help tailor decisions to meet their needs. One important aspect we considered in creating our survey and in moving forward in this arena is properly conveying risk information to patients. Risk perception can be manipulated by the mode of presentation; patients view treatments more favorably when the benefits are explained with relative risk reduction rather than absolute risk reduction (often absolute risk is a smaller number), and rather than number needed to treat (a difficult concept for many patients to comprehend).<sup>60</sup> In our survey, absolute risk reduction was chosen to make the presentation of risk more personalized to the individual patient and show the limits of screening for individuals (an absolute risk reduction of all-cause mortality around 0.5%)<sup>7</sup>. Nearly all respondents (88%) overestimated the benefit of LDCT screening in terms of absolute risk reduction. This same NLST data was used by the USPSTF to determine that a 20% relative reduction in lung cancer mortality was a large enough effect to recommend LDCT screening (with moderate certainty).<sup>8</sup>

I also considered effectiveness of various tools to help explain the NLST numbers during post-interview counseling. In this research I have also learned that choice of illustrative figures and tables can also affect conceptualization of information; for instance, vertical bar charts are significantly better at conveying numerical information than pie charts.<sup>61</sup> With the new USPSTF recommendation, the number of patients seeking LDCT screening will likely increase along with the need to inform patients of their options. An ultimate goal would be to create decision support tools to assist individuals in making choices regarding screening participation.

Lung cancer screening is a very new topic and though the potential harms have been outlined in many reviews, there is still controversy regarding how these harms balance with benefits.<sup>9</sup> As demonstrated in the preceding review, few good-quality studies have been successful and consistent in determining psychological harms associated with lung cancer screening. Additionally, information about patients' understanding of the risks involved in screening is also limited.

I asked whether patients would place great faith in the screening process' ability to improve their well-being. Would they overestimate or underestimate the potential benefits of LDCT screening? Would patients misperceive their personal cancer risk and the risks of LDCT screening? I also asked whether patients would neglect psychological harms and the overall effect on quality of life from participating in lung cancer screening. This study has answered these questions, in a limited sample size, to at least some degree.

The original research presented in this paper was designed to show these misconceptions by using data from the NLST, the trial holding the most weight in the USPSTF's recent decision on lung cancer screening.

**Strengths and limitations.** One strength of this study was the use of a single interviewer to maintain homogeneity of the survey process and results recording. This was also useful in flexibility of the interview process to answer the needed questions in the survey while providing appropriate feedback to individual clinic patients about the screening process and their potential options. The presence of a multi-disciplinary team of researchers in consultation with the study and survey design was integral to developing a survey that would collect meaningful information for our target outcomes.

This study had many weaknesses. It consisted of a convenience sample of 24 participants, and so is limited in power and generalizability, and the findings have a moderate to high degree of uncertainty. The non-random nature of participant recruitment contributes to significant participation bias. The use of knowledge based questions with multiple choice responses is a weakness; in a prior online survey we provided the answer choice “I don’t know,” which was often the most selected option. This study forced participants to choose an option, though many stated during the interview that they did not know the answer. These responses included a wide range from “I’d guess [answer]” to “how could one possibly know that,” and one respondent who becoming visibly angry. Use of multiple choice questions likely introduces some random error in some individuals selecting the correct response. We used ordinal presentation of answer choices to better present information, but this may have led individuals that do not know the answers to select more moderate values, when the answers were often the more extreme choices.

One question (item 20) was particularly difficult to answer; I believe this question was poorly worded and created a hypothetical situation that was several steps down the screening and diagnosis process and was too complex for many to comprehend. The ordinal nature of the

answer choices may have been somewhat leading towards more moderate answer choices, but this presentation was chosen to improve comprehension and flow of the survey.

Asking individuals to estimate their own cancer risk was also very difficult and many respondents were frustrated or made anxious by having to come up with a probability that they would die from cancer in the next six years. Several responded with zero-percent chances, and it was difficult to tell if these responses were actual mental configurations of a probability, or emotional responses representing hope that they would not get cancer.

Our survey was developed by the primary research team; its items did not undergo cognitive testing, and there is significant potential for measurement bias. Some of the steps necessary for a high quality study with good internal validity were bypassed for this study given lack of funding; however, one of the goals of collecting primary data in this study was in grant writing for a future project. This was a pilot study whose data will also be useful in designing future surveys and panel sessions that will be necessary to construct tailored decision aids and counseling services for patients eligible for lung cancer screening.

### **Conclusion:**

Patients eligible for lung cancer screening overestimate their risk of getting, and dying from, lung cancer. They underestimate potential harms and overestimate potential benefits of LDCT screening. The results of this study are important in considering what patients at increased risk of lung cancer understand about the screening process and how they believe screening may benefit or harm them, while considering how they view their personal risk profile. I hope that the experience gained and the responses analyzed here will lead to further meaningful investigation that can help better inform those at increased risk of lung cancer about their options for

screening, so they may make the choice that best fits with their unique risk profile and situation in life.

Future research will be conducted by the research team involved in this study. Assuming LDCT is more widely implemented, given the USPSTF's recommendation, there will be more opportunities to study the effectiveness of lung cancer screening and the psychological implications of LDCT screening for patients. The immediate objectives should be improving on the design of this study to generate better evidence on patient risk perceptions, and their understanding of the screening process. This will allow for development of educational and counselling tools to better inform patients that are considering screening programs. Future research should then focus on developing high quality prospective trials on how such informed-decision making tools perform in allowing patients to make the best decisions for their particular value sets. Scientists should also investigate the long term psychological effects of screening to improve understanding of this category of harms. Finally, due to the increasingly cost-conscious focus of medical and public health systems, wide-scale implementation of LDCT screening should attempt to capture as much information as possible to allow good-quality cost effectiveness analyses of this service at a societal level to demonstrate efficient resource utilization.

## **Tables and Figures**

Appendix 1. Lung cancer screening guidelines. Adapted from UpToDate.<sup>62</sup>

<b>Organization</b>	<b>Recommendation</b>	<b>Year</b>
US Preventive Services Task Force	Recommends annual low-dose CT scan screening for high-risk individuals (ages 55 to 80 years with a 30 pack-year history of smoking and current smoker or quit within past 15 years). Discontinue when person has not smoked for 15 years or if limited life expectancy. <sup>8</sup>	2013
American Cancer Society	Recommends annual low-dose CT scan screening for high-risk individuals (age 55 to 74 years with 30 pack-year history of smoking and current smoker or quit within past 15 years). Informed individual decision making before testing. <sup>63</sup>	2013
American Association of Thoracic Surgery (AATS)	Recommends annual low-dose CT scan screening for high-risk individuals (age 55 to 74 years with 30 pack-year history of smoking and current smoker or quit within past 15 years) or age 50 with cumulative risk >5 percent over next five years. <sup>64</sup>	2012
National Comprehensive Cancer Network	Recommends annual low-dose CT scan screening for high-risk individuals (age 55 to 74 years with 30 pack-year history of smoking or 20 pack-year history with an additional risk factor). <sup>65</sup>	2011
Canadian Task Force on the Periodic Health Examination	Recommends against the use of chest x-ray in asymptomatic persons. Evidence is insufficient to recommend for or against screening with spiral CT in asymptomatic persons. <sup>66</sup>	2003 (under review in 2014)



Table 1. Sample Characteristics (n=24 unless otherwise noted)

Characteristic	% or mean (std dev)	Min- Max
Age	64.63 (6.82)	51-78
Female	50%	
Current Smoker	33%	
Smoking Years	38.8 (10.2)	15-60
Years Since Quit (n=16)	10.4 (8.7)	1-33
Packs Per Day	1.2 (0.48)	0.33-2.5
Pack-Years	43 (15.1)	15.8-75
White	33%	
Black	67%	
COPD or Emphysema	71%	
Asbestos Exposure	50%	
Positive Family History of Lung Cancer (n=23)	35%	
Counseled about screening	17%	
Prior CT Scan	75%	
CT for Screening	4%	
Education: High School or less	63%	
Health Literacy: needs help reading at least sometimes	29%	

Table 2. Correct responses per question

Item number and question asked.	% Correct
19. Out of 1000 people who get screened for lung cancer, about how many will have their lives prolonged?	17
20. Out 1000 people who are screened, about how many will end up getting an invasive procedure, such as a lung biopsy, that doesn't find cancer?	13
21. What percentage of people who get screened for lung cancer will have an abnormal, or "positive," result?	42
22. What percentage of people who have an abnormal, or "positive", result from lung cancer screening DO NOT end up having cancer?	0
23. The chance that getting a CT scan for lung cancer screening will reduce my risk of dying of lung cancer over the next 6 years is.	13

Table 3. Absolute and Comparative Risk Perceptions, (n=23). Estimated risk from Memorial Sloan Kettering Lung Cancer Risk Calculator<sup>46</sup>

	mean % (std dev)	Min-Max	Estimated Risk %
My Risk of getting lung cancer in the next 6 years	26 (30.6)	0-80	n/a
My Risk of dying from lung cancer in the next 6 years <b>with</b> screening	17.5 (22.5)	0-80	1.7
My Risk of dying from lung cancer in the next 6 years <b>without</b> screening	25.1 (29.5)	0-80	2.1
Compared to others at risk for lung cancer, my risk of dying from lung cancer over next 6 years is:	Number	%	
Much less than others	3	13	
Less than others	7	30	
Same	5	22	
More than others	8	35	
Much more than others	0	0	

Table 4. Screening effect on cessation, (n=8)

	Much less likely	Less likely	Same	More likely	Much more likely
Likelihood to quit if in Screening Program			4	3	1
Likelihood to quit if normal screen result			6	2	
Likelihood to quit if in abnormal screen result		1	3	3	1

## **Appendix 2. Survey handout.** (Correct responses to knowledge based questions marked)

### Lung Cancer Screening: Patient Perceptions of Risks vs. Benefits

#### *Study Information*

You have been asked to complete this anonymous survey as part of a research project conducted by Josh Wallace, a graduate student at the University of North Carolina, as part of his degree requirements. This purpose of the research project is to help us understand what patients know about lung cancer screening.

The survey, which will ask you questions about lung cancer screening, should take less than 20 minutes of your time and is voluntary. You may stop taking the survey at anytime, and you may skip any question for any reason. You will not receive any direct benefit from being in this research study. The only possible risk to you of participating in this research study might be embarrassment if your answers became public, but that is very unlikely. All possible measures have been taken to protect the confidentiality of your answers.

We will report only summaries of the aggregated data. This means that your responses will be combined with all of the other responses received and will not be able to be identified as yours. Deductive disclosure, which is the discerning of an individual respondent's identity and responses through the use of known characteristics of that individual, is possible but unlikely.

If you have any questions about this research before or after you complete the survey, please contact Josh Wallace at [joshua\\_wallace@med.unc.edu](mailto:joshua_wallace@med.unc.edu). If you have any concerns or questions about your rights as a participant in this research, please contact the UNC Institutional Review Board at 919-966-3113 or [irb\\_subjects@unc.edu](mailto:irb_subjects@unc.edu).

By completing this survey, you agree to be a participant in this research.

## Lung Cancer Screening Eligibility Assessment Instrument

1. What is your age? \_\_\_\_\_
2. Have you ever been a smoker?  
☐ Yes  
☐ No  
☐ Don't Know/Not Sure
3. Do you smoke cigarettes now?  
☐ Yes  
☐ No

### For FORMER SMOKERS

4. For about how many years were you a smoker? \_\_\_\_
5. About how many cigarettes on average did you smoke per day? *There are 20 cigarettes in a normal pack.* \_\_\_\_\_
6. How long ago did you quit smoking? \_\_\_\_\_

### FOR CURRENT SMOKERS

7. For about how many years have you been a smoker? \_\_\_\_
8. About how many cigarettes on average do you smoke per day? *There are 20 cigarettes in a normal pack.* \_\_\_\_\_

*Pack years = Packs per day \* years as smoker*

### *Eligibility Requirements*

*Age = 50-80*

*Pack years 30 or more*

### *Survey*

Several organizations, such as the American Cancer Society, are now recommending screening for lung cancer using a low dose CT scan for certain people. We are trying to understand what you may know about the new lung cancer screening test. It's okay if you do not know the answers.

### *Risk Status/Eligibility*

9. Is this your first visit to this clinic?

- ☐ Yes
- ☐ No

10. What is the purpose of your visit?

11. Before you came to the clinic: had you ever been counseled about, or had a health care provider ever explained the risks of screening for lung cancer? (Yes/No)

- ☐ Yes
- ☐ No

12. Have you had a CT scan of your chest before?

- ☐ Yes (Answer 4a)
- ☐ No (Answer 4e)

12a. Why was this scan performed (if lung cancer screening, answer 4b-d)?

12b. How many times have you had a CT scan for lung cancer screening?

12c. When was the last time you had a CT scan for lung cancer screening?

12d. What were the results of your CT scan for lung cancer screening?

12e. Has your doctor recommended that you get a CT scan for lung cancer screening?

13. Do you remember the name of the doctor or clinic that referred you here?

- ☐ Yes [WHO? \_\_\_\_\_] ☐ No

For CURRENT SMOKERS:

14. Would you be more or less likely to quit smoking if you participate in a lung cancer screening program?

- ☐ Much less likely to quit
- ☐ Less likely to quit
- ☐ About the same
- ☐ More likely to quit
- ☐ Much more likely to quit

15. How would a normal result from lung cancer screening affect your chances to quit smoking?

- ☐ Much less likely to quit
- ☐ Less likely to quit
- ☐ About the same
- ☐ More likely to quit
- ☐ Much more likely to quit

16. How would an abnormal result from lung cancer screening affect your chances to quit smoking?

- ☐ Much less likely to quit
- ☐ Less likely to quit
- ☐ About the same
- ☐ More likely to quit
- ☐ Much more likely to quit

For ALL:

17. Do you have emphysema or COPD?

☐ Yes

☐ No

18. Have you been exposed to asbestos at work?

☐ Yes

☐ No

*We're going to ask you some questions about what you may or may not know about lung cancer screening for people who meet the screening recommendations.*

19. Out of 1000 people who get screened for lung cancer, about how many will have their lives prolonged?

☐ About 5 (**correct**)

☐ About 20

☐ About 100

☐ 200 or more

20. Out 1000 people who are screened, about how many will end up getting an invasive procedure, such as a lung biopsy, that doesn't find cancer?

☐ 0-10

☐ 10-20

☐ 20-30

☐ 30-40 (**correct**)

☐ More than 40

21. What percentage of people who get screened for lung cancer will have an abnormal, or "positive," result?

☐ Less than 10%

☐ 10-20%

☐ 25-40% (**correct**)

☐ More than 50%

22. What percentage of people who have an abnormal, or "positive", result from lung cancer screening DO NOT end up having cancer?

☐ About 5%

☐ About 25%

☐ About 50%

☐ About 75%

☐ About 95% (**correct**)

*Now we want to know about lung cancer screening and risk of lung cancer for you personally.*

23. The chance that getting a CT scan for lung cancer screening will reduce my risk of dying of lung cancer over the next 6 years is.

- ☐ Less than 1% (**correct**)
- ☐ About 5%
- ☐ About 10%
- ☐ About 20%
- ☐ About 30%

24. My risk for getting lung cancer in the next six years is \_\_\_\_\_

25. My risk for dying from lung cancer in the next six years **WITH** screening is \_\_\_\_\_.

26. My risk for dying from lung cancer in the next six years **WITHOUT** screening is \_\_\_\_\_.

27. Compared to other people at risk for lung cancer, my personal risk:

- ☐ Much lower than average
- ☐ Lower than average
- ☐ About the same as average
- ☐ Higher than average
- ☐ Much higher than average

WHY DO YOU THINK SO?

28. How many people in your family have had lung cancer?

*Next we're going to ask you some questions about lung cancer screening and risk of lung cancer in general.*

29. In your opinion, why might people want get screened for lung cancer?

30. Why might people not want to get screened for lung cancer? *Probe: physical, psychological, financial strain, and opportunity costs.*



*Now I'd like to ask you some questions about yourself.*

31. Are you a:
- ☐ Man
  - ☐ Woman
32. What is your current:
- Height:
- Weight:
33. What race or ethnicity do you consider yourself to be? Choose the one that applies to you most.
- ☐ Latino or Hispanic
  - ☐ American Indian or Alaskan Native
  - ☐ Asian
  - ☐ Black or African-American
  - ☐ Native Hawaiian or Pacific Islander
  - ☐ White
  - ☐ Other \_\_\_\_\_
34. What is the highest grade you have completed?
- ☐ 7<sup>th</sup> grade or lower
  - ☐ 8<sup>th</sup>-11<sup>th</sup> grade
  - ☐ High school graduate or GED
  - ☐ Some college or vocational school
  - ☐ 2 year college degree
  - ☐ 4 year college degree
  - ☐ Professional or graduate degree
35. How often do you need to have someone help you when you read instructions, pamphlets, or other written materials from your doctor or pharmacy?
- ☐ Never
  - ☐ Rarely
  - ☐ Sometimes
  - ☐ Often
  - ☐ Always

## **References:**

1. White C. Research on smoking and lung cancer: A landmark in the history of chronic disease epidemiology. *Yale J Biol Med*. 1990;63(1):29-46.
2. Proctor RN. The history of the discovery of the cigarette-lung cancer link: Evidentiary traditions, corporate denial, global toll. *Tob Control*. 2012;21(2):87-91. doi: 10.1136/tobaccocontrol-2011-050338; 10.1136/tobaccocontrol-2011-050338.
3. U.S. National Library of Medicine. The reports of the surgeon general: The 1964 report on smoking and Health<br />. Profiles of Science: National Library of Medicine Web site. <http://profiles.nlm.nih.gov/ps/retrieve/Narrative/NN/p-nid/60>. Accessed 4/3, 2014.
4. Centers for Disease Control and Prevention (CDC). Cigarette smoking among adults and trends in smoking cessation - united states, 2008. *MMWR Morb Mortal Wkly Rep*. 2009;58(44):1227-1232.
5. North Carolina State Center for Health Statistics. Health profile of north carolinians: 2011 update. N.C. department of health and human services. [http://www.schs.state.nc.us/schs/pdf/HealthProfile2011\\_WEB.pdf](http://www.schs.state.nc.us/schs/pdf/HealthProfile2011_WEB.pdf). Updated 2011. Accessed 4/3, 2014.
6. Humphrey L, Deffebach M, Pappas M, Baumann C, Artis K, Mitchell Jea. Screening for lung cancer: Systematic review to update the U.S. preventive services task force recommendation. *Agency for Healthcare Research and Quality*. 2013;July.
7. The National Lung Screening Trial Research Team. Reduced lung-cancer mortality with low-dose computed tomographic screening. *New England Journal of Medicine*. 2011;365:395-409.

8. Moyer VA. Screening for lung cancer: U.S. preventive services task force recommendation statement. *Ann Intern Med.* 2013. doi: 10.7326/M13-2771; 10.7326/M13-2771.
9. Detterbeck FC, Mazzone PJ, Naidich DP, Bach PB. Screening for lung CancerScreening for lung CancerDiagnosis and management of lung cancer: American college of chest physicians evidence-based clinical practice guidelines. *CHEST Journal.* 2013;143(5\_suppl):e78S-e92S.
10. Paris C, Maurel M, Luc A, Stoufflet A, Pairon JC, Letourneux M. CT scan screening is associated with increased distress among subjects of the APEXS. *BMC Public Health.* 2010;10:647-2458-10-647. doi: 10.1186/1471-2458-10-647; 10.1186/1471-2458-10-647.
11. Cockburn J, De Luise T, Hurley S, Clover K. Development and validation of the PCQ: A questionnaire to measure the psychological consequences of screening mammography. *Soc Sci Med.* 1992;34(10):1129-1134.
12. Horowitz M, Wilner N, Alvarez W. Impact of event scale: A measure of subjective stress. *Psychosom Med.* 1979;41(3):209-218.
13. Gandek B, Ware JE, Aaronson NK, et al. Cross-validation of item selection and scoring for the SF-12 health survey in nine countries: Results from the IQOLA project. *J Clin Epidemiol.* 1998;51(11):1171-1178. doi: [http://dx.doi.org.libproxy.lib.unc.edu/10.1016/S0895-4356\(98\)00109-7](http://dx.doi.org.libproxy.lib.unc.edu/10.1016/S0895-4356(98)00109-7).
14. Kind P, Brooks R, Rabin R. *EQ-5D concepts and methods:: A developmental history.* Springer; 2006.

15. van der Bij AK, de Weerd S, Cikot RJ, Steegers EA, Braspenning JC. Validation of the dutch short form of the state scale of the spielberger state-trait anxiety inventory: Considerations for usage in screening outcomes. *Community Genet.* 2003;6(2):84-87. doi: 73003.
16. Brodersen J, Thorsen H, Kreiner S. Consequences of screening in lung cancer: Development and dimensionality of a questionnaire. . *Value Health.* 2010;13(5):601-612.
17. U.S. Preventive Services Task Force. U.S. preventive services task force (USPSTF) procedure manual. Section 4: Evidence report development. U.S. Preventive Services Task Force Web site. <http://www.uspreventiveservicestaskforce.org/uspstf08/methods/procmanual4.htm>. Accessed 3/15, 2014.
18. U.S. Preventive Services Task Force. U.S. preventive services task force (USPSTF) procedure manual. Appendix VII: Criteria for assessing internal validity of individual studies. U.S. Preventive Services Task Force Web site. <http://www.uspreventiveservicestaskforce.org/uspstf08/methods/procmanualap7.htm>. Accessed 3/18, 2014.
19. U.S. Preventive Services Task Force. U.S. preventive services task force (USPSTF) procedure manual. Appendix VIII: Criteria for assessing external validity (generalizability) of individual studies. U.S. Preventive Services Task Force Web site. <http://www.uspreventiveservicestaskforce.org/uspstf08/methods/procmanualap8.htm>. Accessed 3/18, 2014.
20. U.S. Preventive Services Task Force. U.S. preventive services task force (USPSTF) procedure manual (continued): Section 5: Methods for arriving at a recommendation.

<http://www.uspreventiveservicestaskforce.org/uspstf08/methods/procmanual5.htm>. Accessed 3/24, 2014.

21. Vierikko T, Kivistö S, Järvenpää R, et al. Psychological impact of computed tomography screening for lung cancer and occupational pulmonary disease among asbestos-exposed workers. *European journal of cancer prevention*. 2009;18(3):203; 203-206; 206. doi: 10.1097/CEJ.0b013e328329d800.

22. Mazzone PJ, Obuchowski N, Fu AZ, Phillips M, Mezziane M. Quality of life and healthcare use in a randomized controlled lung cancer screening study. *Ann Am Thorac Soc*. 2013;10(4):324-329. doi: 10.1513/AnnalsATS.201301-007OC; 10.1513/AnnalsATS.201301-007OC.

23. Slatore CG, Press N, Au DH, Curtis JR, Wiener RS, Ganzini L. What the heck is a "nodule"? A qualitative study of veterans with pulmonary nodules. *Ann Am Thorac Soc*. 2013;10(4):330-335. doi: 10.1513/AnnalsATS.201304-080OC; 10.1513/AnnalsATS.201304-080OC.

24. Wiener RS, Gould MK, Woloshin S, Schwartz LM, Clark JA. "What do you mean, a spot?": A qualitative analysis of patients' reactions to discussions with their doctors about pulmonary nodules. *Chest*. 2012;143(3):672.

25. Park ER, Gareen IF, Jain A. Examining whether lung screening changes risk perceptions: National lung screening trial participants at 1-year follow-up. *Cancer*. 2013;119(7):1306-1313.

26. Aggestrup LM, Hestbech MS, Siersma V, Pedersen JH, Brodersen J. Psychosocial consequences of allocation to lung cancer screening: A randomised controlled trial. *BMJ Open*. 2012;2(2).

27. van den Bergh KAM, Essink-Bota M, Borsboom GJ, et al. Short-term health-related quality of life consequences in a lung cancer CT screening trial (NELSON). *Br J Cancer*. 2010;102(1):27; 27-34; 34. doi: 10.1038/sj.bjc.6605459.
28. van den Bergh KAM, Essink-Bota M, Bunge EM, et al. Impact of computed tomography screening for lung cancer on participants in a randomized controlled trial (NELSON trial). *Cancer*. 2008;113(2):396; 396-404; 404. doi: 10.1002/cncr.23590.
29. Bunge EM, van den Bergh KAM, Essink-Bota M, Van Klaveren RJ, de Koning HJ. High affective risk perception is associated with more lung cancer-specific distress in CT screening for lung cancer. *Lung Cancer*. 2008;62(3):385; 385-390; 390.
30. Byrne MM, Weissfeld J, Roberts MS. Anxiety, fear of cancer, and perceived risk of cancer following lung cancer screening. *Med Decis Making*. 2008;28(6):917-925. doi: 10.1177/0272989X08322013; 10.1177/0272989X08322013.
31. Ford ME, Havstad SL, Flickinger L, Johnson CC. Examining the effects of false positive lung cancer screening results on subsequent lung cancer screening adherence. *Cancer Epidemiol Biomarkers Prev*. 2003;12(1):28-33.
32. Vodermaier A. Disease stage predicts post-diagnosis anxiety and depression only in some types of cancer. *Br J Cancer*. 2011;105(12):1814; 1814-1817; 1817.
33. Moher D., Liberati A, Tetzlaff J, Altman D.G., The PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. . *PLoS Med*. 2009;6(6).

34. Kuper A, Lingard L, Levinson W. Critically appraising qualitative research. *BMJ*. 2008;337:a1035. doi: 10.1136/bmj.a1035.
35. U.S. Preventive Services Task Force. U.S. preventive services task force (USPSTF) procedure manual. Table 2. USPSTF levels of certainty regarding net benefit. <http://www.uspreventiveservicestaskforce.org/uspstf08/methods/proctab2.htm>. Accessed 3/24, 2014.
36. Park ER, Gareen IF, Jain A, et al. Examining whether lung screening changes risk perceptions: National lung screening trial participants at 1-year follow-up. *Cancer*. 2013;119(7):1306; 1306-1313; 1313. doi: 10.1002/cncr.27925.
37. Byrne MM, Weissfeld J, Roberts MS. Anxiety, fear of cancer, and perceived risk of cancer following lung cancer screening. *Med Decis Mak*. 2008;28(6):917-925.
38. U.S. Cancer Statistics Working Group. Lung cancer statistics. <http://www.cdc.gov/cancer/lung/statistics/>. Updated Oct, 2013. Accessed 4/10, 2014.
39. Centers for Disease Control and Prevention (CDC). Smoking-attributable mortality, years of potential life lost, and productivity losses--united states, 2000-2004. *MMWR Morb Mortal Wkly Rep*. 2008;57(45):1226-1228.
40. Hyland A, Vena C, Bauer J, Li Q, Yang J, Cummings K. Cigarette smoking-attributable morbidity --- united states, 2000. *Morb.Mortal.Wkly.Rep*. 2003;52(35):842-844.
41. Styn MA, Land SR, Perkins KA, Wilson DO, Romkes M, Weissfeld JL. Smoking behavior 1 year after computed tomography screening for lung cancer: Effect of physician referral for

- abnormal CT findings. *Cancer Epidemiol Biomarkers Prev.* 2009;18(12):3484-3489. doi: 10.1158/1055-9965.EPI-09-0895; 10.1158/1055-9965.EPI-09-0895.
42. Taylor KL, Cox LS, Zincke N, Mehta L, McGuire C, Gelmann E. Lung cancer screening as a teachable moment for smoking cessation. *Lung Cancer.* 2007;56(1):125; 125-134; 134.
43. McMahon PM, Kong CY, Bouzan C, et al. Cost-effectiveness of computed tomography screening for lung cancer in the united states. *J Thorac Oncol.* 2011;6(11):1841-1848. doi: 10.1097/JTO.0b013e31822e59b3; 10.1097/JTO.0b013e31822e59b3.
44. Bach PB, Mirkin JN, Oliver TK, et al. Benefits and harms of CT screening for lung cancer: A systematic review. *JAMA.* 2012;307(22):2418-2429. doi: 10.1001/jama.2012.5521; 10.1001/jama.2012.5521.
45. Aggestrup LM, Hestbech MS, Siersma V, Pedersen JH, Brodersen J. Psychosocial consequences of allocation to lung cancer screening: A randomised controlled trial. *BMJ Open.* 2012;2(2):e000663-2011-000663. Print 2012. doi: 10.1136/bmjopen-2011-000663; 10.1136/bmjopen-2011-000663.
46. Memorial Sloan Kettering Cancer Center. Lung cancer screening decision tool. <http://nomograms.mskcc.org/Lung/Screening.aspx>. Accessed 3/24, 2014.
47. Kovalchik S, Tammemagi M, Berg CD. Targeting of low-dose CT screening according to the risk of lung-cancer death. . *New England Journal of Medicine.* 2013;369(3):245-254.
48. Sinicrope P. Perceptions of lung cancer risk and beliefs in screening accuracy of spiral computed tomography among high-risk lung cancer family members. *Acad Radiol.* 2010;17(8):1012.



49. Schnoll RA, Bradley P, Miller SM, Unger M, Babb J, Cornfeld M. Psychological issues related to the use of spiral CT for lung cancer early detection. *Lung Cancer*. 2003;39(3):315-315-325; 325.
50. van den Bergh KA, Essink-Bot ML, van Klaveren RJ, de Koning HJ. Informed participation in a randomised controlled trial of computed tomography screening for lung cancer. *Eur Respir J*. 2009;34(3):711-720. doi: 10.1183/09031936.00098908; 10.1183/09031936.00098908.
51. Messer K, Trinidad DR, Al-Delaimy WK, Pierce JP. Smoking cessation rates in the united states: A comparison of young adult and older smokers. *Am J Public Health*. 2008;98(2):317-322. doi: 10.2105/AJPH.2007.112060; 10.2105/AJPH.2007.112060.
52. Ostroff JS, Buckshee N, Mancuso CA, Yankelevitz DF, Henschke CL. Smoking cessation following CT screening for early detection of lung cancer. *Prev Med*. 2001;33(6):613; 613-621; 621.
53. Taylor KL, Cox LS, Zincke N, Mehta L, McGuire C, Gelmann E. Lung cancer screening as a teachable moment for smoking cessation. *Lung Cancer*. 2007;56(1):125-134.
54. Ashraf H, Tonnesen P, Holst Pedersen J, Dirksen A, Thorsen H, Dossing M. Effect of CT screening on smoking habits at 1-year follow-up in the danish lung cancer screening trial (DLCST). *Thorax*. 2009;64(5):388-392. doi: 10.1136/thx.2008.102475; 10.1136/thx.2008.102475.
55. McMahon PM, Kong CY, Bouzan C, et al. Cost-effectiveness of computed tomography screening for lung cancer in the united states. *J Thorac Oncol*. 2011;6(11):1841-1848. doi: 10.1097/JTO.0b013e31822e59b3; 10.1097/JTO.0b013e31822e59b3.

56. Balint E. The possibilities of patient-centered medicine. *J R Coll Gen Pract.* 1969;17(82):269-276.
57. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean?(or it takes at least two to tango). *Soc Sci Med.* 1997;44(5):681-692.
58. Eddy DM. Anatomy of a decision. *JAMA.* 1990;263(3):441-443.
59. Sheridan S, Harris R, Woolf S. Shared decision making about screening and chemoprevention. *American Journal of Preventive Medicine.* 2004;26(1):56-66.
60. Covey J. A meta-analysis of the effects of presenting treatment benefits in different formats. *Med Decis Making.* 2007;27(5):638-654. doi: 10.1177/0272989X07306783.
61. Feldman-Stewart D, Brundage MD, Zotov V. Further insight into the perception of quantitative information: Judgments of gist in treatment decisions. *Med Decis Making.* 2007;27(1):34-43. doi: 10.1177/0272989X06297101.
62. UpToDate. Guidelines for lung cancer screening.  
[http://www.uptodate.com/contents/image?imageKey=PULM/64078&topicKey=PC%2F7566&source=outline\\_link&search=lung+cancer+screening&utdPopup=true](http://www.uptodate.com/contents/image?imageKey=PULM/64078&topicKey=PC%2F7566&source=outline_link&search=lung+cancer+screening&utdPopup=true). Accessed 3/17, 2014.
63. Wender R, Fontham ETH, Barrera Jr. E, et al. American cancer society lung cancer screening guidelines. *CA Cancer J Clin.* 2013;63(2):106-117.
64. Jaklitsch MT, et al. The american association for thoracic surgery guidelines for lung cancer screening using low-dose computed tomography scans for lung cancer survivors and other high-risk groups. *J Thorac Cardiovasc Surg.* 2012;144(1):33; 33-38; 38.

65. National Comprehensive Cancer Network. NCCN guidelines for patients: Lung cancer screening. [http://www.nccn.org/patients/guidelines/lung\\_screening/index.html#12/z](http://www.nccn.org/patients/guidelines/lung_screening/index.html#12/z). Updated 2014. Accessed 3/17, 2014.
66. Palda V, Van Spall H. Screening for lung cancer: Updated recommendations from the canadian task force on preventive health care . . 2003;Aug.

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